

United States Organ Transplantation

OPTN / SRTR

2012
ANNUAL DATA REPORT

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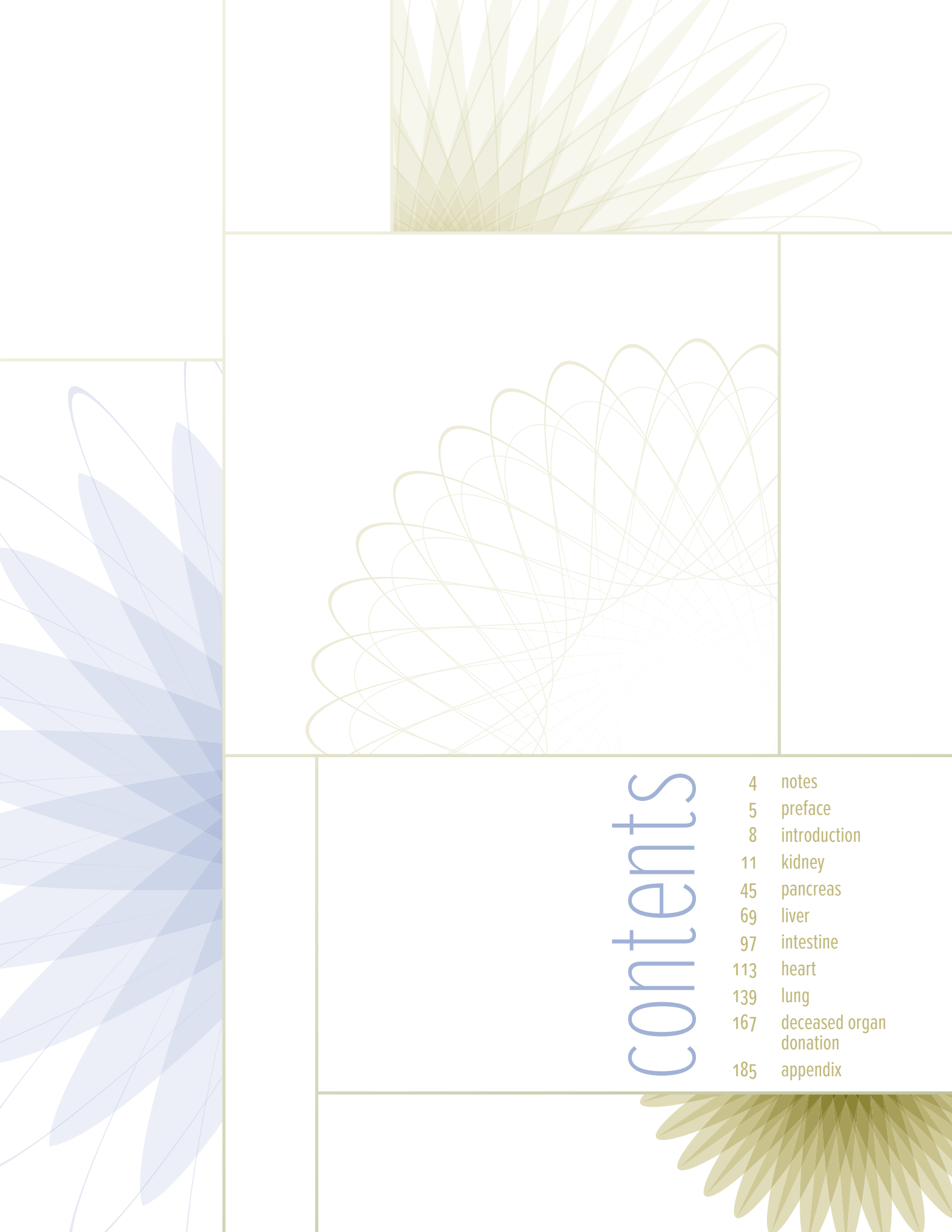
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This report is available at srtr.transplant.hrsa.gov. Individual chapters, as well as the report as a whole, may be downloaded.



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notes

POPULATIONS REPORTED

Figure titles indicate adult or pediatric populations; if not specified, data include all patients of all ages.

Unless otherwise specified, data in each organ-specific chapter include both isolated transplants and multi-organ transplants of the given type. For example, patients on the kidney transplant waiting list include those listed for an isolated kidney, kidney-pancreas, or any other organ combination that includes kidney.

Wait-list populations are reported at the person level. If a patient is listed at more than one center, we concatenate those records from the time of earliest listing to the time of latest removal. Patients listed, removed (usually due to transplant), and subsequently re-listed are counted separately per concatenated listing.

AGE

Adult patients are defined as those aged 18 years or older for all organs except lung; lung allocation policy treats patients aged 12 years or older as adults. For wait-list figures, age is defined at the time of listing unless otherwise specified.

RACE/ETHNICITY

Multi-racial patients are defined as other/unknown. When a given race group is not shown, it is included with other/unknown.

ECD KIDNEYS

Data on willingness to accept an ECD kidney are available from 2003.

PANCREAS DATA

Pancreas data encompass the three types of pancreas waiting lists or transplants: simultaneous kidney-pancreas (SPK), pancreas after kidney (PAK), and pancreas-alone (PTA). Pancreata used for islet transplantation are excluded.

LUNG ALLOCATION SCORE

The lung allocation score (LAS) became available in 2005. Data by LAS are presented using the most recent LAS before December 31 of each year. In the case of transplant recipients, data by LAS are presented using the LAS at the time of transplant.

Figure titles specify adult and pediatric populations; if not listed, figure includes patients of all ages. (For lung data, patients aged 12 and older are grouped with adults.)

Each chapter contains (when relevant to the specific organ) the following sections:

- wait list
- deceased donation
- live donation
- transplant
- donor-recipient matching
- outcomes
- immunosuppression
- pediatric transplant
- Medicare data
- maps of transplant centers

preface

This Annual Data Report of the US Organ Procurement and Transplantation Network (OPTN) and the Scientific Registry of Transplant Recipients (SRTR) is the twenty-second annual report and is based on data pertaining to the period 1998-2012. The title OPTN/SRTR 2012 Annual Data Report reflects the fact that the report covers the most recent complete year of transplants, those performed in 2012.

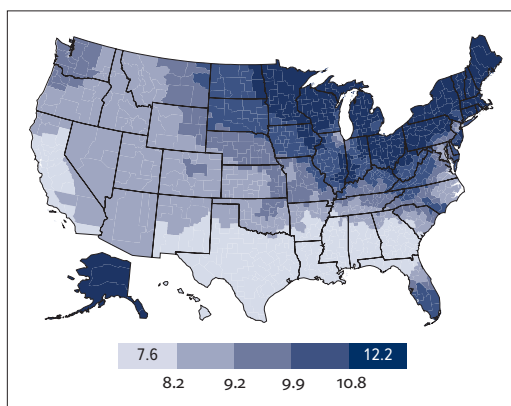
As the SRTR contractor, the Minneapolis Medical Research Foundation, through its Chronic Disease Research Group, determined which data to present, conducted the required analyses, created the figures and tables, drafted the text, and designed the document. As the OPTN contractor, the United Network for Organ Sharing reviewed the draft report, contributed to the content, and provided the glossary.

OVERVIEW AND HIGHLIGHTS

This Annual Data Report includes chapters on kidney, pancreas, liver, intestine, heart, and lung transplantation, a chapter on deceased donor organ donation, and an appendix. The organ-specific chapters include information on such topics as the waiting list, deceased donor organ donation, living donor organ donation, transplant, donor-recipient matching, outcomes, immunosuppression, and pediatric transplant. New this year is information on cost, including data on Medicare payments, in most organ chapters. When possible, similar data and formats are used for each chapter. However, this is not always possible because some data are not pertinent to all organs.

Graphical presentation of the data is emphasized: approximately 400 figures, tables, and maps are included in the various chapters. Graphics are downloadable as slides srtr.transplant.hrsa.gov. The data behind the graphics are downloadable from the same location in a spreadsheet format. Numerous data tables are also provided on the site.

Maps in this report present data divided into quintiles. Below is a sample map.



In this example, approximately one-fifth of all data points have a value of 10.8 or above. Ranges include the number at the lower end of the range, and exclude that at the upper end (e.g., the second range here is 8.2 to < 9.2). To facilitate comparisons of maps for different periods, we commonly apply a single legend to each map in a series. In this case, the data in each individual map are not evenly distributed, and a map for a single year may not contain all listed ranges. Numbers in the first and last boxes indicate the mean values of data points in the

highest and lowest quintiles, not the minimum and maximum of observed data.

Maps by donation service area (DSA) use DSA boundaries in effect at the end of 2012. Some DSAs include non-contiguous areas. If a DSA has no transplant program for a given organ, the DSA is not shaded on the map.

On the SRTR website, the Excel page for each map includes additional data. The map-specific mean is calculated using only the population included in the map; this does not usually match other data in the Annual Data Report, and should be quoted with caution. The overall mean includes all patients for whom data are available, whether or not their residency, transplant center, or DSA is known. We also include the number of patients excluded in the map-specific mean, and the total number of patients used in the calculation.

MILESTONE DATES IN THE PRODUCTION OF THIS REPORT

Data were cut: April 2013.

Data were analyzed: May 2013.

DATA REQUESTS TO THE SRTR

Requests for data can be made to SRTR at <http://www.srtr.org/> or to OPTN at <http://optn.transplant.hrsa.gov>.

WEBSITES

[HTTP://WWW.SRTR.ORG](http://www.srtr.org) is a public website containing transplant program-specific reports, organ procurement organization (OPO)-specific reports, summary tables, archives of past reports, timelines for future reports, risk-adjustment models, methods, basic references for researchers who use SRTR data files, a link to the Annual Data Report and its supporting documentation and data tables, answers to frequently asked questions, and other information.

[HTTPS://SECURESRTR.TRANSPLANT.HRSA.GOV](https://securesrtr.transplant.hrsa.gov) is a secure website that provides access to the prerelease program- and OPO-specific reports, survival spreadsheets, and other useful information. All individual authorized users from transplant programs and OPOs have their own unique logins for the secure site.

[HTTP://UNOS.ORG](http://unos.org) is a public website containing information on donation and transplantation, data collection instruments, data reports, education materials for patients and transplant professionals, policy development, and other information. This website also links to the OPTN website.

[HTTP://OPTN.TRANSPLANT.HRSA.GOV](http://optn.transplant.hrsa.gov) is a public website containing news, information, and resources about transplantation and donation, including transplant data reports; policy development; and related boards and committees. It also contains allocation calculators, a calendar of events, answers to frequently asked questions, and other information

CONTACT INFORMATION**PATIENT INQUIRIES**

888-894-6361 (toll free)

RESEARCH INQUIRIES

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introduction

An imbalance continues between the supply of organs for transplant and the number of patients registered on deceased donor transplant waiting lists. Differences in supply and demand for different organs are highlighted below; also discussed are changes in wait-list activity, transplants performed, and discard of organs recovered for transplant.

TRENDS IN DECEASED DONOR TRANSPLANT WAITING LISTS

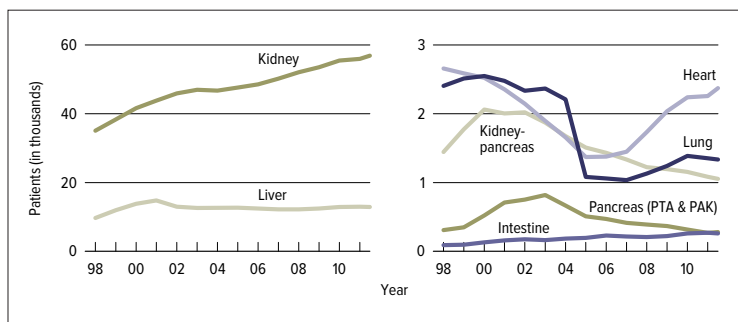
Separate waiting lists are maintained for each deceased donor organ allocated for transplant by the Organ Procurement and Transplantation Network. The numbers of new patients listed for transplant every year differ by organ type. In making comparisons, it is important to note that patients who need a kidney and, to a lesser extent, patients who need a

liver may undergo living donor transplant and never appear on the deceased donor waiting list. Others who ultimately undergo living donor transplant may have been listed on the deceased donor waiting list.

The kidney transplant waiting list is the largest solid organ waiting list by far (Figure 1a). On December 31, 2012, 57,903 active candidates were wait-listed for kidney transplant, 1021 for simultaneous pancreas-kidney (SPK) transplant, 290 for pancreas transplant alone (PTA) or pancreas after kidney (PAK) transplant, 12,774 for liver transplant, 251 for intestine transplant, 2,493 for heart transplant, and 1,315 for lung transplant. Of note, in 2005, a new allocation system based on the lung allocation score (LAS) was implemented in an attempt to allow sicker patients to undergo lung transplants more quickly. With implementation of this new system, many patients who would not undergo transplant were removed from the lung transplant waiting list, resulting in an abrupt decline in the number of candidates listed (Figure 1a). In addition, some patients are listed for multiple organs and appear on more than one waiting list.

The number of active (prevalent) candidates on the kidney transplant waiting list increased 3.5% between December 31, 2011, and December 31, 2012, from 55,969 to 57,903 (Figure 1a). The numbers of prevalent candidates on the waiting list at the end of the year declined in 2012 compared with 2011 for liver (-1.8%), SPK (-5.9%), intestine (-7.7%), and lung (-2.9%) transplants, but increased for PTA/PAK (7.8%) and heart transplants (10.4%).

The number of new (active and inactive) candidates added to the deceased donor kidney waiting list increased 2.9% between 2011 and 2012 (Figure 1b). The annual numbers of candidates added to the waiting lists also increased for SPK (6.6%) and



INT 1a Patients on the waiting list on December 31 of the year (active listings only)

All except PA: Patients waiting for a transplant. A "new patient" is one who first joins the list during the given year, without having listed in a previous year. However, if a patient has previously been on the list, has been removed for a transplant, and has relisted since that transplant, the patient is considered a "new patient." Patients concurrently listed at multiple centers are counted only once. Those with concurrent listings and active at any program are considered active; those inactive at all programs at which they are listed are considered inactive. PA only: Patients waiting for a transplant. A "new patient" is one who first joins one of the three lists during the given year, without having listed in a previous year. However, if a patient has previously been on the list, has been removed for a transplant, and has relisted since that transplant, the patient is considered a "new patient." Patients concurrently listed at multiple centers or on more than one list are counted only once. Those with concurrent listings and active at any program are considered active; those inactive at all programs at which they are listed are considered inactive.

heart (5.6%) transplants, but declined for PTA/PAK (-12.2%), lung (-4.5%), and liver (-2.3%) transplants.

In summary, the most notable wait-list trends over the past decade have been the continuing gradual increases in the numbers of candidates waiting for a kidney on the deceased donor waiting list. In contrast, the number of candidates waiting for pancreas transplants has steadily declined. The most rapidly growing waiting list has been for heart transplants.

TRENDS IN ORGAN TRANSPLANTS

For 3 years in a row, the total number of kidney transplants performed in the US has declined. Between 2011 and 2012, the number declined by 1.8%, from 17,607 to 17,287 (Figure 2). This decline in transplants is probably not due to a declining demand for kidneys, since many more candidates were active on the waiting list than underwent transplant. On December 31, 2012, for example, 57,903 candidates were active on the deceased donor kidney waiting list, approximately 3-fold more than underwent transplant in 2012. The situation is not improving, since in 2012 many more patients were added to the deceased donor kidney transplant waiting list (20,093 active, 31,157 active plus inactive) than underwent transplant.

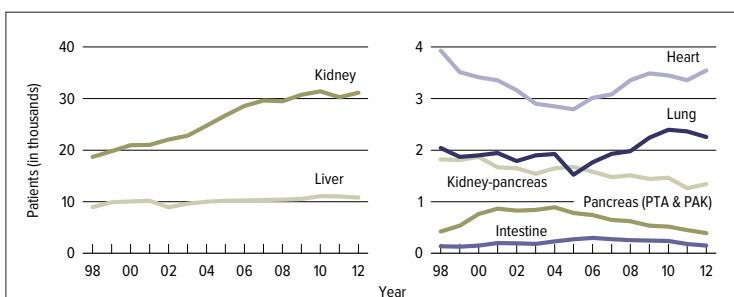
The number of pancreas transplants has declined markedly and progressively. Between 2011 and 2012, the total number of pancreas transplants (pancreas alone or combined with a kidney) performed in the US declined by 3.6%, from 1082 to 1043. Since the peak of 1484 pancreas transplants performed in 2004, numbers have declined annually. Reasons for this decline are unclear, but it parallels a decline in the number of patients listed, rather than in the number of donors.

The number of liver transplants performed declined by 6.3%, from a peak of 6651 in 2006 to 6256 in 2012. This represents a decline of about 1% per year. The number of lung transplants decreased by 3.6%, from 1849 in 2011 to 1783 in 2012, the first time since 2002 that this number has declined. The number of heart transplants increased 2.5% between 2011 and 2012.

In summary, the numbers of abdominal organ transplants have been flat or have declined over the past 5 years, while the numbers of heart and lung transplants have increased.

DISCARDS

A general shortage of most deceased donor organs for transplant continues. A frequently asked question is how often organs removed for transplant



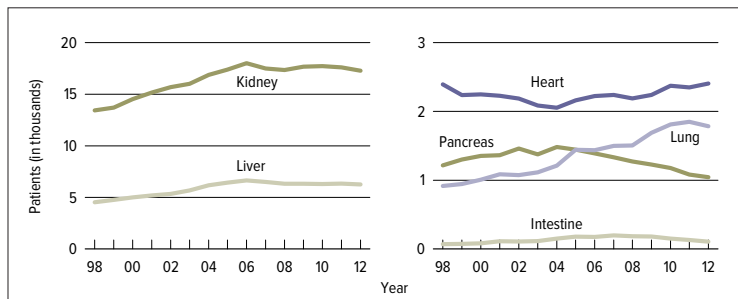
INT 1b Patients added to the waiting list during the year (active & inactive at listing)

All except PA: Patients waiting for a transplant. A “new patient” is one who first joins the list during the given year, without having listed in a previous year. However, if a patient has previously been on the list, has been removed for a transplant, and has relisted since that transplant, the patient is considered a “new patient.” Patients concurrently listed at multiple centers are counted only once. Those with concurrent listings and active at any program are considered active; those inactive at all programs at which they are listed are considered inactive. PA only: Patients waiting for a transplant. A “new patient” is one who first joins one of the three lists during the given year, without having listed in a previous year. However, if a patient has previously been on the list, has been removed for a transplant, and has relisted since that transplant, the patient is considered a “new patient.” Patients concurrently listed at multiple centers or on more than one list are counted only once. Those with concurrent listings and active at any program are considered active; those inactive at all programs at which they are listed are considered inactive.

are subsequently discarded. The answer varies for different organs, and discards occur for different reasons (Figure 3). The discard rate is highest (25% to 30%) for pancreata. This is undoubtedly because the shortage of pancreata is not as critical as for other organs. Hence, patients and their physicians can wait for a high-quality pancreas. Since 2005, the annual percentage of discarded pancreata has changed little.

The least-often discarded organ is the heart, followed by lung and liver. This is because these organs are seldom removed from a deceased donor unless a recipient has already been found. The discard rate for lungs is approximately 5%, and the rate for hearts is less than 1%. The liver discard rate is approximately 10%, and has changed little since 2005.

The discard rate for kidneys is about 18%, and has changed little in the past several years. The most common reason given for discarding a kidney recovered for transplant is the biopsy result. This result may be somewhat biased, since biopsies are more likely to be obtained when the donor kidney is suspected of being suboptimal. An argument can be made that biopsies, which have been shown to be poor predictors of graft outcomes, should be used less often.

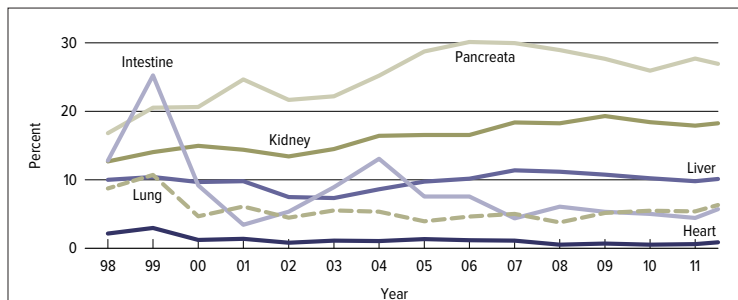


INT 2 Transplants performed during the year (adult & pediatric combined)

Kidney: Patients receiving a kidney-alone or simultaneous kidney-pancreas transplant. Lung: Patients receiving a lung-alone or simultaneous heart-lung transplant. Other organs: Patients receiving a transplant. Retransplants are counted.

SUMMARY

The number of kidney transplants has declined 3 years in a row, despite growth in the number of new patients added to the deceased donor kidney waiting list, both active and total (active plus inactive). The reasons for this worrisome trend are unknown, and they represent an ongoing source of controversy. This is particularly true given the relatively high rate at which kidneys removed for the purpose of transplant are discarded. Even more dramatic has been the decline in pancreas transplants, which has occurred despite an adequate source of deceased donor pancreata. This could reflect better alternative treatments for diabetes or other factors leading to less demand. The most rapid change in solid organ transplantation has been in heart and lung transplants.



INT 3 Discard rates among organs recovered for transplant

Percent of organs discarded out of all organs recovered for transplant. Kidney: Kidneys are counted individually. The reference population for the KDRP conversion is all deceased donor kidneys recovered for transplant in the US in 2012. Lung: Lungs recovered as a block are counted as one organ. Lungs recovered separately are counted as two organs.

Corrected after online publication on 16 September 2014. Figure INT 2 has been corrected, and the text of the “Trends in Organ Transplants” section has been updated.

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OPTN/SRTR 2012 Annual Data Report:

kidney

ABSTRACT : For most end-stage renal disease patients, successful kidney transplant provides substantially longer survival and better quality of life than dialysis, and preemptive transplant is associated with better outcomes than transplants occurring after dialysis initiation. However, kidney transplant numbers in the US have not changed for a decade. Since 2004, the total number of candidates on the waiting list has increased annually. Median time to transplant for wait-listed adult patients increased from 2.7 years in 1998 to 4.2 years in 2008. The discard rate of deceased donor kidneys has also increased, and the annual number of living donor transplants has decreased. The number of pediatric transplants peaked at 899 in 2005, and has remained steady at approximately 750 over the past 3 years; 40.9% of pediatric candidates undergo transplant within 1 year of wait-listing. Graft survival continues to improve for both adult and pediatric recipients. Kidney transplant is one of the most cost-effective surgical interventions; however, average reimbursement for recipients with primary Medicare coverage from transplant through 1 year posttransplant was comparable to the 1-year cost of care for a dialysis patient. Rates of rehospitalization are high in the first year posttransplant; annual costs after the first year are lower.

KEY WORDS End-stage renal disease, kidney transplant, organ allocation, waiting list.

So much of what I talk to people about is the hope that I have because of donation. It gives us something positive to do. Our son is still "out there." It is a thrill that people continue to get to know him. People will never forget him, he will live on in all these people.

donor mom

Introduction

For most end-stage renal disease (ESRD) patients aged younger than 70 years (and for selected patients aged 70 years or older), a successful kidney transplant provides substantially longer survival and better quality of life than dialysis. For patients who undergo transplant, preemptive transplant (before maintenance dialysis begins) is associated with better results than transplant after 6 months of dialysis, and for each additional year of pretransplant dialysis, posttransplant outcomes are worse.

Given these observations, it is striking that in the United States, kidney transplant numbers have changed little over the past decade, and have actually declined slightly in the last 3 years. This chapter's Figures 1-6 show 2012 Organ Procurement and Transplantation Network (OPTN) data on the adult kidney transplant waiting list and kidney transplants in the US. Figures 1.1-1.14 show data on the waiting list and change over time, Figures 2.1-2.7 deceased donation, Figures 3.1-3.6 living donation, Figures 4.1-4.7 and 5.1-5.7 transplant rates and recipient demographics, and Figures 6.1-6.13 transplant outcomes.

Adults

WAITING LIST

Since 2004, the total number of candidates on the waiting list has increased annually (Figure 1.1), mostly due to added inactive candidates. Increased numbers of inactive candidates in part reflect the change in OPTN policy in 2003 permitting inactive candidates to accumulate waiting time points. This policy change eliminated the disincentive to list candidates as inactive. Of candidates who were inactive within 7 days of listing, 72.5% were inactive because of incomplete work-up, 8.8% because of insurance issues, 7.5% because of being too sick, and 4.6% because candidate weight was inappropriate

for transplant (Figure 1.3). In contrast, for candidates who were listed as active but were inactive as of December 31, 2012, 31.1% were inactive because of incomplete work-up and 35.3% because of being too sick. Given the long waiting times for a deceased donor transplant (and the associated morbidity and mortality), some centers list all candidates as inactive because of incomplete work-up and perform the work-up only when the candidates near the top of the list.

From 2002 to 2012, most candidate demographics have changed little (Figures 1.4, 1.5). The only significant trends have been a steady increase in the number of candidates aged 50 years or older (particularly those aged 65 years or older) added to the waiting list, and a steady decrease in the percentage of candidates of white race on the waiting list. Importantly, over the past decade, for all age groups and diagnoses, the number of transplants per 100 active wait-list years has decreased; however, the numbers of candidates with panel-reactive antibodies (PRA) $\geq 20\%$, and particularly $\geq 80\%$, have increased, reflecting OPTN policy changes to give priority to these difficult-to-match candidates (Figure 1.7). The combination of a growing candidate list and decreasing transplant rates has resulted in more than 21,000 candidates being removed from the waiting list in the last 3 years because of death or becoming too sick to undergo transplant (Figure 1.9). This is an area of potential research. Three-year outcomes for candidates listed in 2009 show that 43.0% were still waiting in 2012, 9.3% had died, 8.4% were removed from the list because of being too sick, and 39.3% had undergone transplant (Figure 1.10). The percentage of candidates who underwent transplant after 3 years was highest in the 18-35 year age group; the percentage of candidates removed from the list because of death or being too sick increased with candidate age.

A striking (but not new) observation is the tremendous difference between organ procurement organizations in kidney transplant rates (both living donor and deceased donor) per 100 years on the waiting list (Figure 1.8) and in the percentage of wait-listed patients who undergo deceased donor kidney transplant within 5 years (Figure 1.12). This is also an area of potential research.

Perhaps the best depiction of the current state of kidney transplantation in the US is the median time to transplant for wait-listed adult patients, which increased from 2.7 years in 1998 to 4.2 years in 2008 (Figure 1.11). Given the morbidity and mortality associated with prolonged dialysis (especially for some subgroups, e.g., patients with diabetes or aged older than 60 years), these long waits are associated with only a minority surviving to undergo transplant.

Donation

A concerning observation, especially considering the tremendous shortage of organs, is the increased rate of deceased donor discards by donor type (donation after brain death [DBD], standard criteria donor [SCD], expanded criteria donor [ECD]) (Figures 2.3, 2.4). This could be attributed to increased willingness by organ procurement organizations to procure kidneys from borderline donors in the hope that the kidneys would be usable for transplant; however, this does not explain the increasing rate of SCD kidney discards (Figure 2.4). This question could be investigated further.

Concurrently, the annual number of living donor transplants from relatives steadily decreased (Figure 3.1). This cannot be explained by an increase in spouse, partner, or unrelated donor transplants. Further research could yield insight on this matter. The total annual number of living donor transplants decreased from a peak of 6647 in 2004

to 5622 in 2012 (Figure 3.1). Living donation has been relatively stable among white donors; the decrease has been more pronounced among black, Hispanic, and Asian donors (Figure 3.2). Whether this is due to changing demographics or to other factors has not been determined. Again, further research could yield insight.

In the past decade, living donor death rates have not changed (Figure 3.6), although reported complications have increased. Whether this is a true increase or due to increasing OPTN emphasis on following early donor outcomes is unclear.

TRANSPLANT

As noted above, living donor transplants have decreased, and deceased donor transplants have increased only slightly since 2005 (Figure 4.1). Numbers of transplants have increased only for candidates aged 50 years or older during this interval (Figures 4.2, 4.6). For all subgroups, approximately 14.5% of all transplants are now donation after circulatory death (DCD) transplants. Immunosuppressive medication protocols have changed little recently. Most recipients are treated with tacrolimus and a mycophenolate; 64.2% receive a T-cell depleting agent; and about 30% are steroid-free at transplant and at 1 year posttransplant.

OUTCOMES

On the positive side, for both living and deceased donor transplants, death-censored graft failure in the first 90 days has steadily decreased and continues to decrease (Figure 6.1). Similarly, 6 month and 1-, 3-, 5-, and 10-year graft survival has slowly but steadily improved (Figures 6.3, 6.4). Most of the improvement relates to decreased donor graft loss (graft failure or return to dialysis). Rates of death with function have

changed little; this may represent some improvement in that it is generally believed that patients with more comorbid conditions are undergoing transplant.

Five-year graft survival for deceased donor transplants was 73% in 2012, and was similar for SCDs and DCDs (Figure 6.5). Recipients with glomerulonephritis or cystic disease as primary cause of ESRD had better 5-year outcomes than recipients with diabetes or hypertension (however, data are not controlled for demographic factors such as age and comorbid conditions). Five-year survival for living donor transplants was 84% (Figure 6.6), and was better for recipients with glomerulonephritis or cystic disease than for those with diabetes or hypertension. Graft survival was lower for black recipients than for white recipients or members of others racial groups). Importantly, 5-year graft survival differed little between related and unrelated living donor transplant recipients.

For both living and deceased donor transplants, the half-life of the kidney allograft has slowly but steadily improved, as has the half-life of grafts with 1-year graft survival (Figure 6.7). Of note, the rate of posttransplant diabetes dropped from a peak of 11.4% at 1-year posttransplant in 2005 to 6.1% in 2011 (Figure 6.11). The reasons for this are unclear. The percentage of recipients treated with steroid-free protocols changed little, but possibly recipients treated with steroids receive much lower doses than in 2005 (an area of potential research). Doses (levels) of other immunosuppressive agents may also be lower.

Consistent with the 2011 report, risk of developing posttransplant lymphoproliferative disorders (PTLD) over the first 5 years posttransplant was higher for recipients who are Epstein-Barr virus (EBV) negative at transplant, although the cumulative risk is 1.3% (Figure 6.12).

PUBLIC POLICY CONSIDERATIONS

The total number of kidney transplants in the US has not changed appreciably for a decade, despite increasing numbers of candidates on the waiting list, the knowledge that a successful transplant provides longer life and better quality of life than dialysis, and the fact that transplant (versus dialysis) saves costs for the health care system.

In the early 1990s, the Organ Donation Breakthrough Collaborative was initially associated with a significant increase in the rate of deceased donor transplants; however, since the mid-1990s, although use of ECD and DCD donors has increased, deceased donor kidney transplant rates have not increased. No new public policy initiatives to increase donation have occurred. Instead, the major focus of public policy has been on developing methods of increasing patient survival post-transplant. In accordance with the Final Rule, OPTN has been trying to develop a new allocation system that improves both access to transplant and patient survival. Several deceased donor kidney allocation proposals have been advanced; for each, an underlying theme has been to allocate the best kidneys to the best patients (as defined by the kidney donor risk index and estimated long-term patient survival, respectively). In June 2013, the OPTN Board of Directors approved a new kidney allocation system that was nearly a decade in the making. Although this new allocation policy is expected to improve patient survival and broaden access to transplant, it will not address the shortage of donor kidneys. Clearly, additional efforts are needed to expand the supply of donated organs, and to use donated organs more effectively.

Initiatives in living donation have included the development of nondirected donation, paired exchange, and successful desensitization protocols. Each of these raises associated ethical questions, and importantly, adds substantial work

load to transplant center personnel. Despite these developments, the overall living donation rate decreased 15% from 2004 to 2012.

Is it time to energize another major public policy initiative to increase organ donation? Increased donation rates could possibly decrease mortality on the waiting lists and would save costs for the health care system. The major challenge would be gathering the appropriate government and nongovernment groups into a forum to discuss potential changes.

Children and Adolescents

WAITING LIST

In 2012, just over half of new pediatric candidates added to the kidney transplant waiting list were listed as inactive (Figure 7.1). This number has continued to increase since the policy change in 2003 permitting waiting time to accrue while candidates are listed as inactive. The most common reason for inactive status for new candidates, given for 64.3%, was incomplete work-up (Figure 7.2). Similarly, prevalent wait-listed patients listed as inactive outnumbered those listed as active (Figure 7.1). The most common reasons for inactive status for prevalent candidates included being too sick (25.0%), being too well (24.5%), and incomplete work-up (19.8%) (Figure 7.2). By age, the largest proportion of wait-list candidates were aged 11-17 years (69.0%), followed by those aged 1-5 years (15.9%) (Figure 7.3). While the proportions of white and Asian candidates remained relatively constant, the proportion of Hispanic candidates increased and the proportion of black candidates decreased. Most pediatric candidates on the waiting list (62.6%) had < 1% PRA. The etiology of ESRD remains relatively constant; structural abnormalities are the most common cause in the youngest patients, and focal segmental glomerulosclerosis and glomerulonephritis increase in frequency with

increasing age (Figure 7.4). Length of time on the waiting list changed remarkably little; 40.9% of candidates waited less than 1 year, 25.3% 1-< 2 years, 16.7% 2-<4 years, and 17.1% > 4 years (Figure 7.3).

In 2012, 12.8% of pediatric candidates on the kidney transplant waiting list had undergone a previous kidney transplant (Figure 7.5). Of all wait-list candidates in 2012, 2.7% of those aged younger than 6 years, 15.6% of those aged 6-10 years, and 15.4% of those aged 11-17 years were waiting for retransplant. Of pediatric candidates on the waiting list in 2012, 25.8% received a deceased donor kidney by the end of the year, 9.7% received a living donor kidney, 1.3% died, 0.4% were removed from the list because their condition improved, and 0.2% were considered too sick to undergo transplant (Figure 7.6). The rate of deceased donor transplant among pediatric wait-list candidates was 106 per 100 active wait-list years, with similar rates among all age groups (Figure 7.8). However, transplant rates vary significantly by calculated PRA (CPRA); the highest rates are for candidates with < 1% CPRA (198 transplants per 100 active wait-list years) and the lowest for candidates with > 80% CPRA (20 transplants per 100 active wait-list years). In contrast to mortality among patients waiting for other organs, pretransplant mortality among pediatric patients waiting for kidney transplant is low, 1.86 per 100 wait-list years in 2010-2012 (Figure 7.9).

TRANSPLANT

The number of pediatric kidney transplants peaked in 2005 at 899 and remained steady at approximately 750 over the past 3 years (Figure 7.10). In 2012, the number of deceased donor transplants continued to outnumber the number of living donor transplants, 474 to 287, respectively. Retransplant accounted for 9.6% of deceased donor transplants and 7.7%

of living donor transplants among pediatric recipients in 2012 (Figure 7.11). Only 3.2% of pediatric kidney transplants were part of a multi-organ transplant, in contrast to 8.0% of adult transplants (Figure 7.12).

Donation from related living donors declined, while donation from other living donors increased, possibly reflecting increased participation in living donor exchanges (Figure 7.13). The youngest recipients undergo the highest percentage of living donor transplants (Figure 7.13). In 2012, DCD kidneys were used in < 5% of pediatric kidney transplants (Figure 7.14). ECD kidneys are rarely used in pediatric recipients; only 1 case was reported in 2012, and none from 2007-2011.

The age of deceased donor organs allocated to pediatric transplant recipients has changed over time, guided by changes in both clinical practice and allocation policy. In October 2005, United Network for Organ Sharing (UNOS) implemented a revised allocation policy known as Share 35 that required renal allografts from deceased donors aged less than 35 years to be offered preferentially to patients aged less than 18 years. Figure 7.15 illustrates the increase in deceased donor organs from donors aged less than 35 years following implementation of Share 35.

The number of HLA mismatches increased over time, raising concerns about long-term graft survival. Among deceased donor kidney transplant recipients in 2012, 85% had > 3 HLA mismatches. In contrast, 19.5% of living donor recipients had > 3 HLA mismatches in 2012 (Figure 7.17).

IMMUNOSUPPRESSIVE MEDICATION USE

Trends in maintenance immunosuppressive medications used in children and adolescents are similar to trends for adults. In 2012, 93.8% of pediatric transplant recipients received tacrolimus as part of the initial maintenance immu-

nosuppressive medication regimen, and 93.4% received mycophenolate mofetil (Figure 7.22). In 2011, 5.7% of recipients received mammalian target of rapamycin inhibitors at 1 year posttransplant; corticosteroids were used in 64.5% of transplant recipients at the time of transplant and in 66.3% at 1 year posttransplant. Induction therapy has also changed substantially over time in pediatric kidney transplantation. A decrease in use of interleukin-2 receptor antagonist therapy for induction was accompanied by a corresponding increase in the use of T-cell depleting agents, used in 56.2% of recipients in 2012. The percentage of recipients receiving no induction therapy continued to decline, reaching a low of 12.2% in 2012.

OUTCOMES

Graft survival (survival with a functioning graft) continued to improve over the past decade. Graft failure estimates for deceased donor transplants were 1.8% at 6 months and 2.7% at 1 year for transplants in 2011-2012, 13.8% at 3 years for transplants in 2009-2010, 26.2% at 5 years for transplants in 2007-2008, and 50.8% at 10 years for transplants in 2001-2002 (Figure 7.23). Corresponding graft failure estimates for living donor transplants were 2.5% at 6 months and 2.9% at 1 year for transplants in 2011-2012, 7.7% at 3 years for transplants in 2009-2010, 16.7% at 5 years for transplants in 2007-2008, and 34.7% at 10 years for transplants in 2001-2002 (Figure 7.24). The rate of late graft failure is traditionally measured by the graft half-life conditional on 1-year survival, defined as the time to when half of grafts surviving at least 1 year are still functioning. For deceased donor transplants, the 1-year conditional graft half-life was 12.5 years for transplants in 2009-2010; for living donor transplants, the 1-year conditional half-life was 15.3 years for transplants in 2009-2010 (Figure 7.26).

Rehospitalization among transplants in 2007-2012 occurred for 52.8% of patients in the first year after transplant (Figure 7.20).

PTLD is a major concern in pediatric transplantation. The highest risk for PTLD is in EBV-negative recipients of EBV-positive donor kidneys. This occurred in 36.1% of deceased donor transplants and 36.2% of living donor transplants in 2008-2012 (Figure 7.18). The incidence of PTLD among EBV-negative recipients was 4.1% at 5 years posttransplant, compared with 0.6% among EBV-positive recipients (Figure 7.21).

The combination of a cytomegalovirus positive donor and negative recipient occurred in 34.5% of deceased donor kidney transplants and 28.2% of living donor transplants (Figure 7.19).

The incidence of acute rejection among pediatric patients undergoing kidney transplant 2006-2011 increased over time posttransplant (Figure 7.27). At 1 year posttransplant, 14% of deceased donor recipients and 9% of living donor recipients experienced first acute rejection episode.

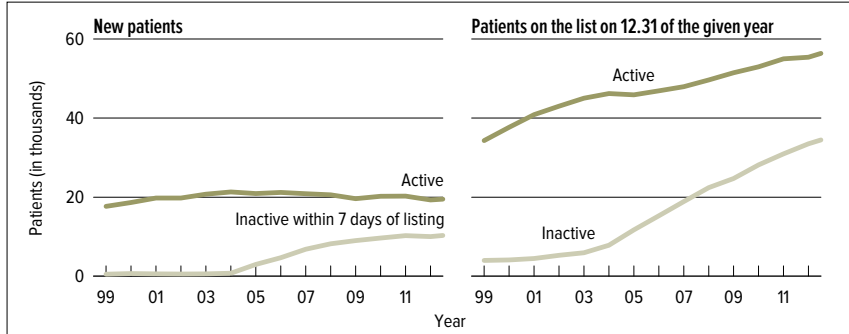
Short-term renal function, measured by estimated glomerular filtration rate (eGFR), improved substantially over the past decade. The proportions of patients with eGFR > 90 mL/min/1.73 m² at discharge increased from 17.1% in 2000 to 34.6% in 2012, at 6 months posttransplant from 10.3% in 2000 to 26.3% in 2012, and at 1 year posttransplant from 6.7% in 2000 to 25.9% in 2011 (Figure 7.28). Almost 70% of recipients in the 2012 cohort had chronic kidney disease stage 1-2 at discharge, with eGFR > 60 mL/min/1.73 m². For the 2011 cohort, this was almost 71% at 6 months and 72% at 12 months posttransplant.

Economics

Kidney transplant remains one of the most cost-effective surgical interventions. However, it is not without considerable direct economic cost. Average reimbursement for kidney

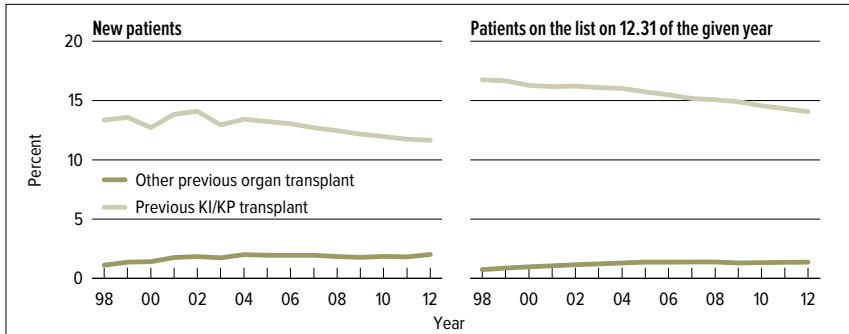
transplant recipients with primary Medicare coverage from transplant through 1 year posttransplant was \$63,432 for Part A and \$19,969 for Part B (Figure 8.5), totaling \$83,401, comparable to the 1-year cost of care for a dialysis patient. Rehospitalization is a primary driver behind inter-patient variation in cost of care. Rates of rehospitalization are relatively high in the first year posttransplant (Figure 8.2) and drop by half in the second year (Figure 8.3). Primary causes of rehospitalization are dominated by transplant complications and infections in both the first and second years posttransplant (Figure 8.4). Annual costs following the first year are dramatically smaller; Medicare Part A and B costs average \$14,427 and \$11,157, respectively during year 2 (Figure 8.6). The total, \$25,584, is expected to remain stable in later years and is approximately one-half to one-third the total annual cost of care for a dialysis patient. Additional costs are not accounted for here, including reimbursement to hospitals for the transplant portion of the Medicare Cost Report and Medicare Part D. Including estimates for these costs raises the average Medicare cost to approximately \$200,000 in the first year posttransplant and approximately \$30,000 in subsequent years. Although kidney transplant is the least expensive per patient of all solid organ transplants, kidney transplant recipients account for 64% of all Medicare Part A and B expenditure following solid organ transplant, or \$2.6 billion, \$26,947 per patient in 2010 (Figure 8.7).

wait list



KI 1.1 Adult patients waiting for a kidney transplant

Patients waiting for a transplant. A “new patient” is one who first joins the list during the given year, without having listed in a previous year. However, if a patient has previously been on the list, has been removed for a transplant, and has relisted since that transplant, the patient is considered a “new patient.” Patients concurrently listed at multiple centers are counted only once. Those with concurrent listings and active at any program are considered active; those inactive at all programs at which they are listed are considered inactive.



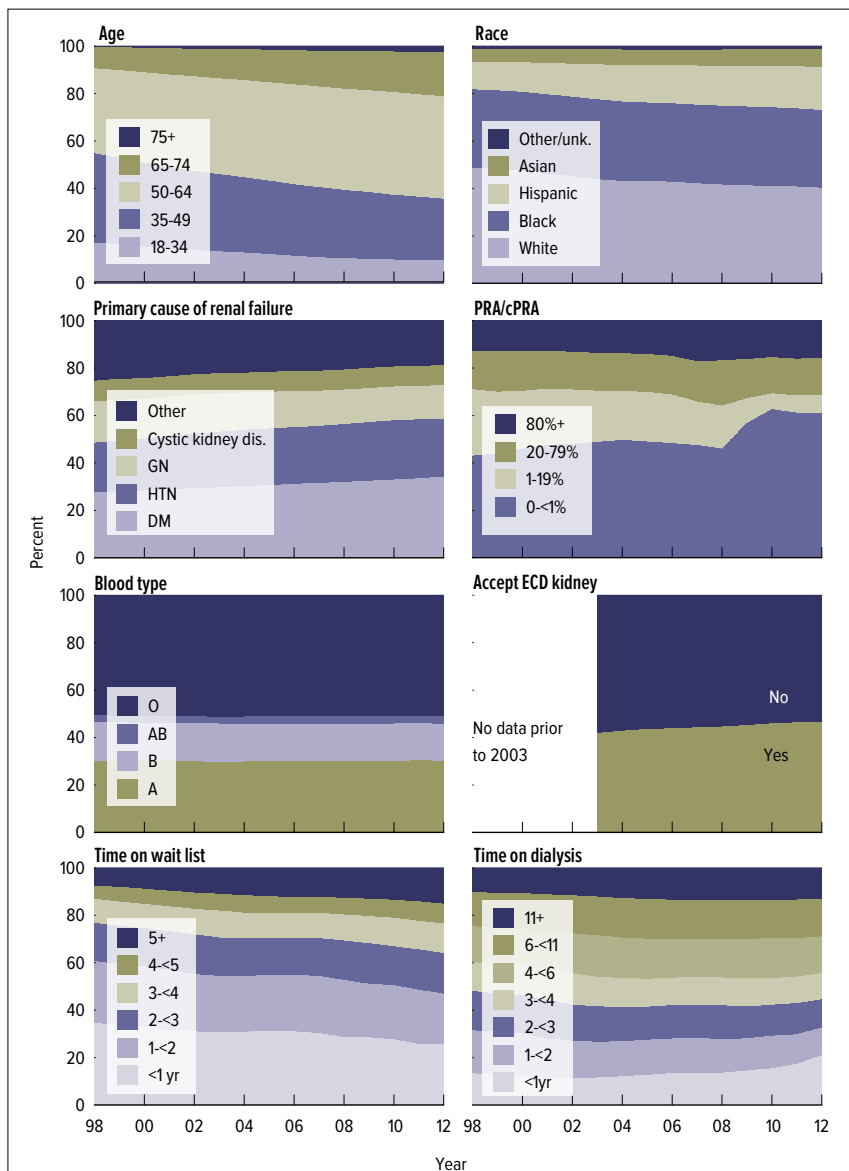
KI 1.2 Prior kidney transplant in patients waiting for a kidney transplant

Prior transplant status of patients waiting for a KI or KP transplant. Prior kidney transplant defined as kidney or kidney-pancreas transplant. Other solid organ transplant defined as all other organs beside kidney or kidney-pancreas. Prevalent patients as of December 31 of each year. Each patient is counted only once.

Reason for inactive status	Inactive w/i 7 days of listing		Active at listing, inact. on 12.31	
	N	%	N	%
Candidate work-up incomplete	9,370	72.5	6,052	31.1
Insurance issues	1,076	8.3	1,707	8.8
Too sick	975	7.5	6,876	35.3
Weight inappropriate for tx	589	4.6	1,096	5.6
Too well	384	3.0	951	4.9
Candidate choice	286	2.2	1,059	5.4
Tx pending	104	0.8	45	0.2
Medical non-compliance	75	0.6	662	3.4
Inappropriate substance use	50	0.4	271	1.4
Physician/surgeon unavailable	6	0.0	4	0.0
Unknown	4	0.0	359	1.8
Candidate could not be contacted	3	0.0	374	1.9

KI 1.3 Reasons for inactive status among kidney transplant listings, 2012

Reasons for inactive status of listings in 2012. Since patients can be concurrently listed at more than one center and have different reasons for going inactive at each center, each listing is counted separately.



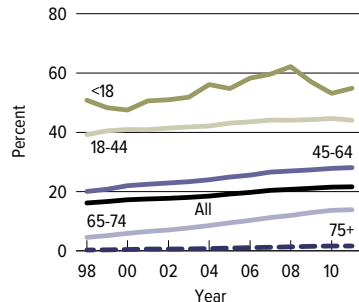
KI 1.4 Distribution of adult patients waiting for a kidney transplant
 Patients waiting for a transplant any time in the given year. Age determined on the earliest of listing date or December 31 of the given year. Concurrently listed patients are counted once.

	Level	2002		2012	
		N	%	N	%
Age	18-34	7,147	14.0	8,811	9.5
	35-49	17,323	34.0	24,799	26.7
	50-64	20,340	39.9	40,523	43.6
	65-74	5,661	11.1	16,779	18.1
	75+	533	1.0	1,973	2.1
Sex	Male	29,334	57.5	55,104	59.3
	Female	21,670	42.5	37,781	40.7
Race	White	21,106	41.4	35,189	37.9
	Black	18,345	36.0	31,607	34.0
	Hispanic	7,406	14.5	17,536	18.9
	Asian	3,445	6.8	7,218	7.8
	Other/unk.	702	1.4	1,335	1.4
Primary cause of disease	DM	14,501	28.4	31,801	34.2
	HTN	12,362	24.2	23,209	25.0
	GN	8,389	16.4	13,068	14.1
	Cyst. kid	4,265	8.4	7,591	8.2
	Oth/unk	11,487	22.5	17,216	18.5
Tx hist.	List 1st tx	41,884	82.1	79,376	85.5
	List sub. tx	9,120	17.9	13,509	14.5
Blood type	A	14,211	27.9	26,814	28.9
	B	8,580	16.8	14,832	16.0
	AB	1,375	2.7	2,665	2.9
	O	26,838	52.6	48,574	52.3
PRA & CPRA	<20%	36,494	71.6	79,982	86.1
	≥20%	14,509	28.4	12,903	13.9
	Unknown	1	0.0	0	0.0
Time on list	<1 year	17,542	34.4	26,374	28.4
	1-<2	11,825	23.2	19,994	21.5
	2-<3	8,318	16.3	15,722	16.9
	3-<4	5,221	10.2	10,883	11.7
	4-<5	3,131	6.1	7,018	7.6
	5+	4,967	9.7	12,894	13.9
ECD kidney	W/N accept			49,832	53.6
	Will accept			43,053	46.4
Multiple listings	Kidney alone	48,664	95.4	90,808	97.8
	Kid/Pancreas	2,340	4.6	2,077	2.2
	Total	51,004	100	92,885	100

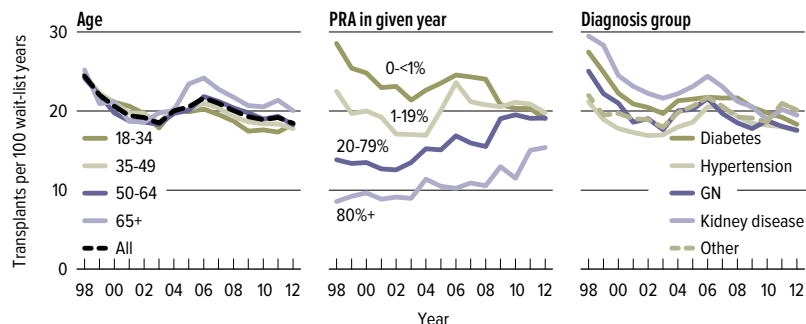
KI 1.5 Characteristics of adult patients on the kidney transplant waiting list on December 31, 2002 & December 31, 2012

Patients waiting for a transplant on December 31, 2002 and December 31, 2012, regardless of first listing date; active/inactive status is on this date, and multiple listings are not counted.

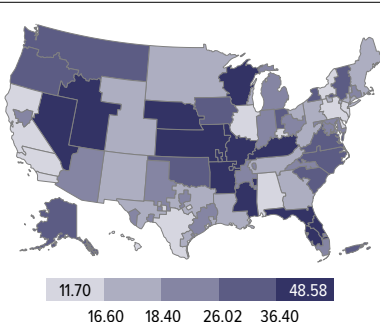
wait list


KI 1.6 Prevalent dialysis patients wait-listed for a kidney transplant, by age

Prevalent dialysis patients, all ages, wait-listed for a kidney-alone transplant. Percentage calculated as the sum of wait-list patients divided by the sum of point prevalent dialysis patients on December 31 of each year (data from the United States Renal Data System).


KI 1.7 Deceased donor kidney transplant rates among active adult waiting list candidates

Transplant rates are computed as the number of deceased donor transplants per 100 patient-years of active waiting time in a given year. Age is calculated on the first active listing date in a given year. The most recent PRA is used prior to 2007. If most recent PRA was not provided, peak PRA is reported. Between 2007 and 2009, PRA is used when it is available and CPRA otherwise, because PRA was used in allocation. After 2009, when CPRA started being used in allocation, CPRA is reported.

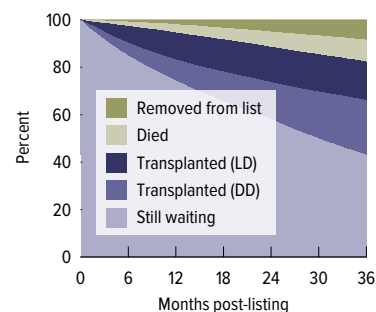

KI 1.8 Deceased donor kidney transplant rates per 100 patient years on the waiting list among active adult candidates, by DSA, 2011-2012

Transplant rates by DSA of the listing center, limited to those with active time on the waiting list in 2011 and 2012; deceased donor transplants only. Maximum time per listing is two years. Patients with concurrent listings in a single DSA are counted once in that DSA, and those listed in multiple DSAs are counted separately per DSA.

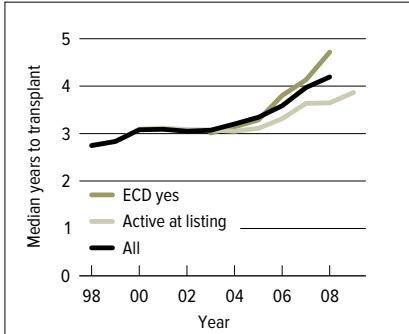
	2010	2011	2012
Patients at start of year	81,099	85,948	88,874
Patients added during year	30,564	29,361	30,274
Patients removed during year	25,672	26,399	26,263
Patients at end of year	85,991	88,910	92,885
Removal reason			
Deceased donor transplant	10,826	11,195	11,033
Living donor transplant	5,346	5,009	4,934
Tx (type not specified)	56	49	58
Patient died	5,302	5,440	5,209
Patient refused transplant	339	406	413
Improved, tx not needed	103	138	148
Too sick to transplant	1,533	1,873	2,062
Other	2,167	2,289	2,406

KI 1.9 Kidney transplant waiting list activity among adult patients

Patients with concurrent listings at more than one center are counted once, from the time of earliest listing to the time of latest removal. Patients listed, transplanted, and re-listed are counted more than once. Patients are not considered "on the list" on the day they are removed. Thus, patient counts on January 1 may be different from patient counts on December 31 of the prior year. Patients listed for multi-organ transplants are included. Known deaths following removal for being too ill are counted as deaths.

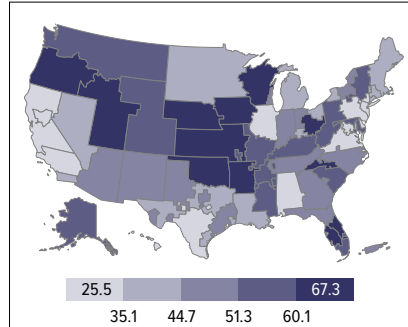

KI 1.10 Three-year outcomes for adult patients waiting for a kidney transplant among new listings in 2009

Adult patients waiting for any kidney transplant and first listed in 2009. Patients with concurrent listings at more than one center are counted once, from the time of the earliest listing to the time of latest removal.



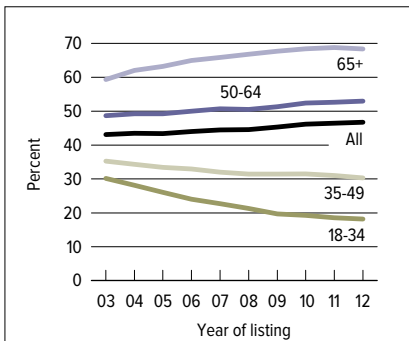
KI 1.11 Median years to kidney transplant for wait-listed adult patients

Patients waiting for a transplant, with observations censored at December 31, 2012; Kaplan-Meier methods used to estimate time to transplant. If an estimate is not plotted, 50% of the cohort listed in that year had not been transplanted at the censoring date. Only the first transplant is counted.



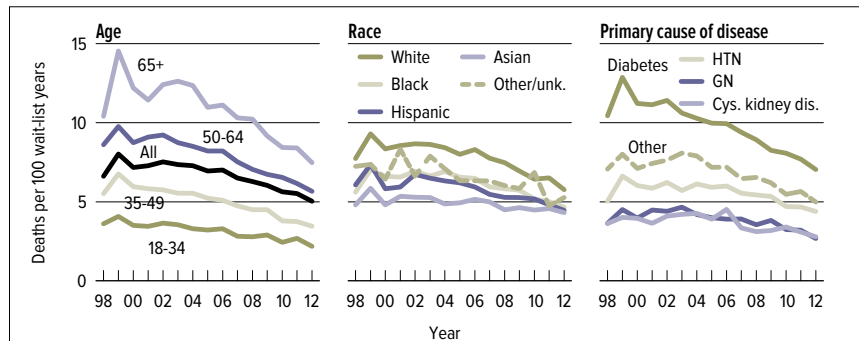
KI 1.12 Percent of adult wait-listed patients, 2007, who received a deceased donor kidney transplant within five years, by DSA

Patients with concurrent listings in a single DSA are counted once in that DSA, and those listed in multiple DSAs are counted separately per DSA.



KI 1.13 Adult patients willing to accept an ECD kidney, by age

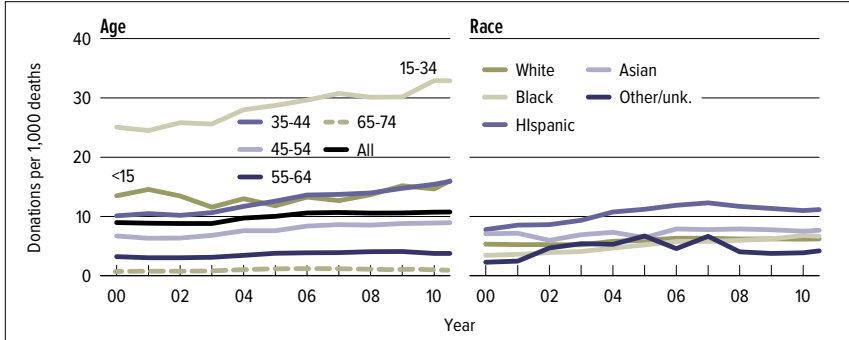
Period-prevalent adult patients waiting for any kidney transplant, 2003 (beginning of ECD program) to 2012. Patients with concurrent listings at more than one center are counted once, from the time of the earliest listing to the time of latest removal. If at least one listing will accept an ECD, patient is considered willing to accept ECD.



KI 1.14 Pre-transplant mortality rates among adult patients wait-listed for a kidney transplant

Patients waiting for a transplant. Mortality rates are computed as the number of deaths per 100 patient-years of waiting time in the given year. For rates shown by different characteristics, waiting time is calculated as the total waiting time in the year for patients in that group. Only deaths that occur prior to removal from the waiting list are counted. Age is calculated on the latest of listing date or January 1 of the given year. Other patient characteristics come from the OPTN Transplant Candidate Registration form.

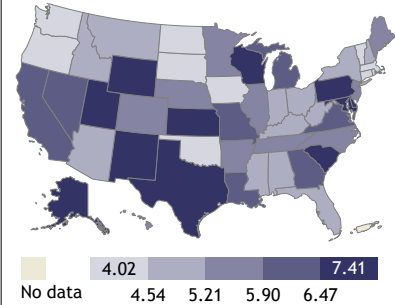
deceased donation



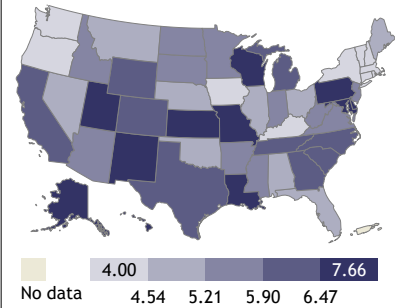
KI 2.1 Deceased donor kidney donation rates

Numerator: Deceased donors age less than 75 with at least one kidney recovered for transplant. Denominator: US deaths per year, age less than 75. (Death data available at <http://www.cdc.gov/nchs/products/nvsr.htm>.) Death data were available only through 2011.

2006–2008

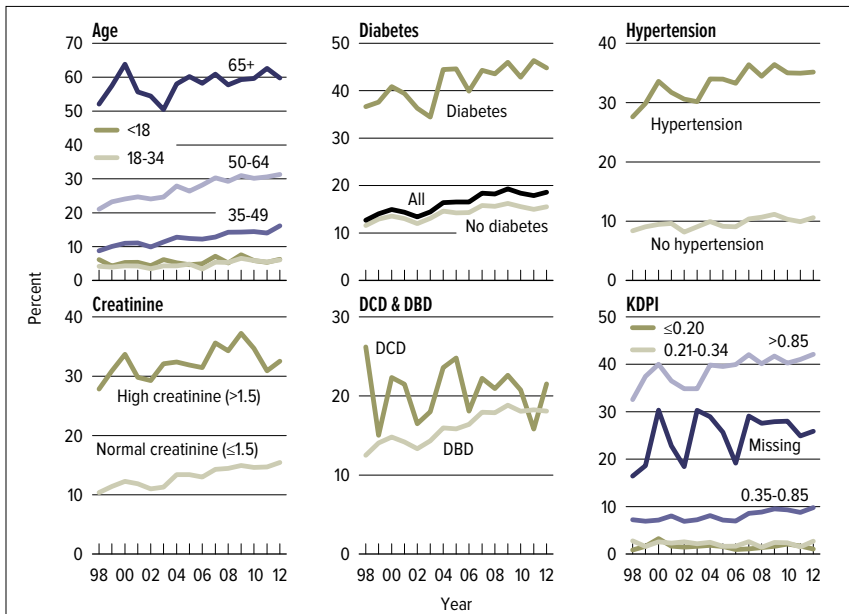


2009–2011



KI 2.2 Deceased donor kidney donation rates (per 1,000 deaths), by state

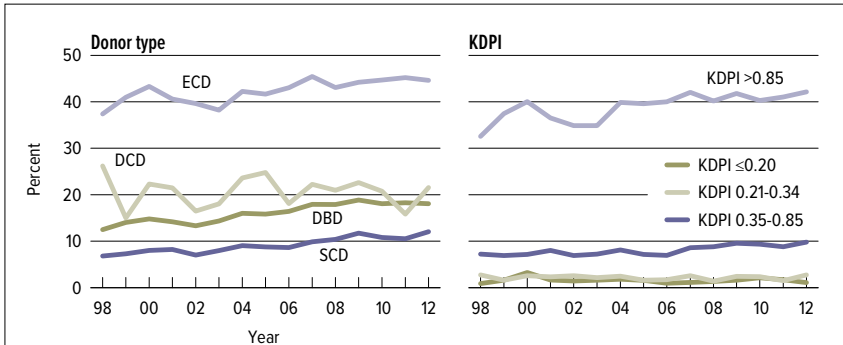
Numerator: Deceased donors residing in the 50 states whose kidney(s) was/were recovered for transplant in the given year range. Denominator: US deaths by state during the given year range (death data available at <http://www.cdc.gov/nchs/products/nvsr.htm>). Rates are calculated within ranges of years for more stable estimates. Donors who donated two kidneys are counted twice.



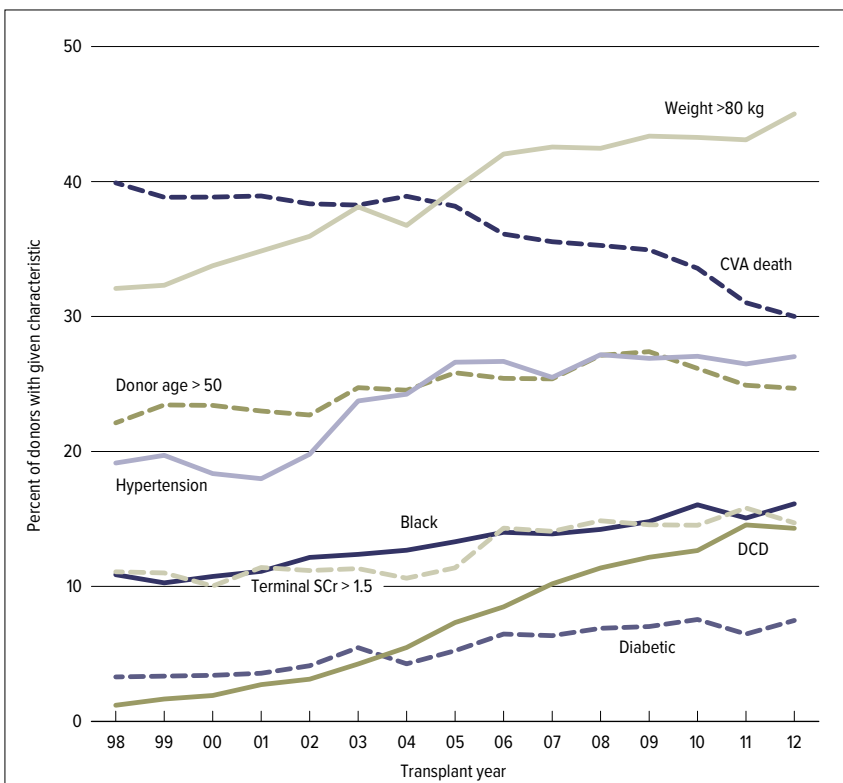
KI 2.3 Discard rates for kidneys recovered for transplant

Percent of kidneys discarded out of all kidneys recovered for transplant. Kidneys are counted individually. The reference population for the KDPI conversion is all deceased donor kidneys recovered for transplant in the US in 2012.

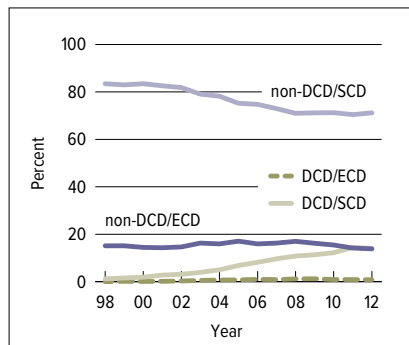
deceased donation



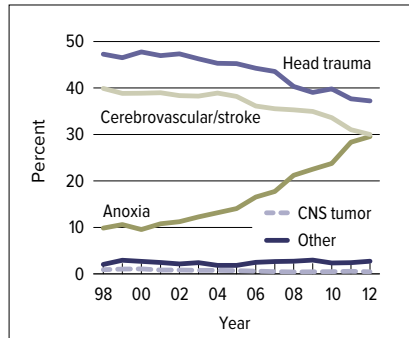
KI 2.4 Discards by donor type (SCD, ECD, DCD, ECD & DCD)
 Percent of kidneys discarded out of all kidneys recovered for transplant, by SCD/ECD, DCD/DBD, and KDPI classification of donor. The reference population for the KDRI to KDPI conversion is all deceased donor kidneys recovered for transplant in the US in 2012.



KI 2.5 Donor-specific components of kidney donor risk index (KDRI) over time
 Donors with at least one kidney transplanted are included. The donor-specific components of KDRI (Kidney Donor Risk Index) are shown, with the exception of donor height and HCV+ status.

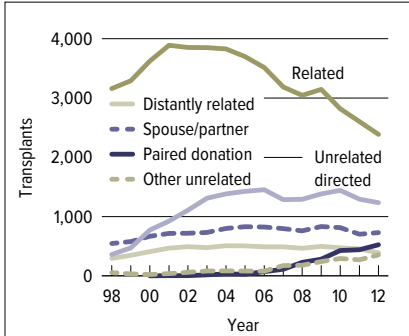


KI 2.6 DCD with ECD or SCD kidney transplants
 Percent of each kidney type among all deceased-donor kidney-alone transplants.



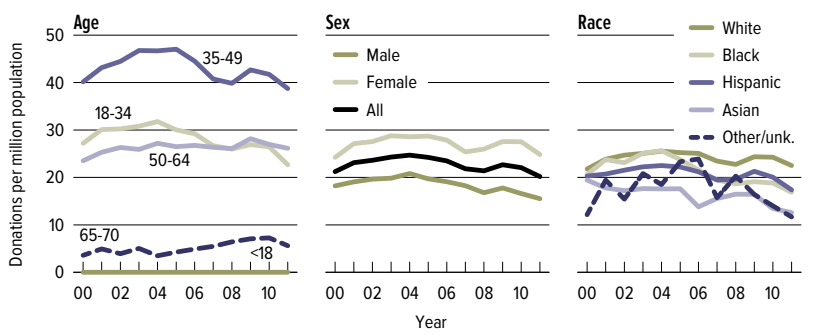
KI 2.7 Cause of death among deceased kidney donors
 Deceased donors whose kidneys were transplanted. Donors who contributed more than one kidney are counted once. CNS = central nervous system.

live donation



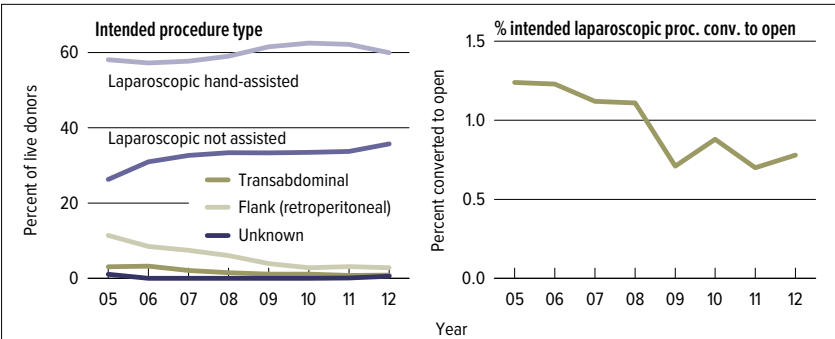
KI 3.1 Kidney transplants from living donors, by donor relation

Number of living donor donations; characteristics recorded on OPTN Living Donor Registration form.



KI 3.2 Living donor kidney donation rates

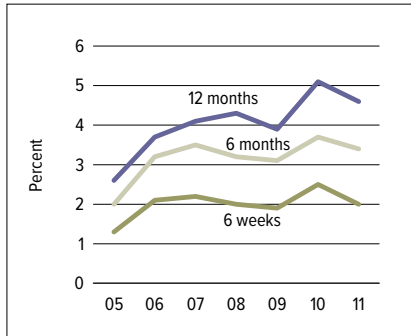
Number of living donors whose kidney was recovered for transplant each year. Denominator: us population age 70 and younger (population data downloaded from http://www.cdc.gov/nchs/nvss/bridged_race/data_documentation.htm#vintage2011).



KI 3.3 Intended kidney transplant procedure type & percent of intended laparoscopic procedures converted to open, 2006–2012

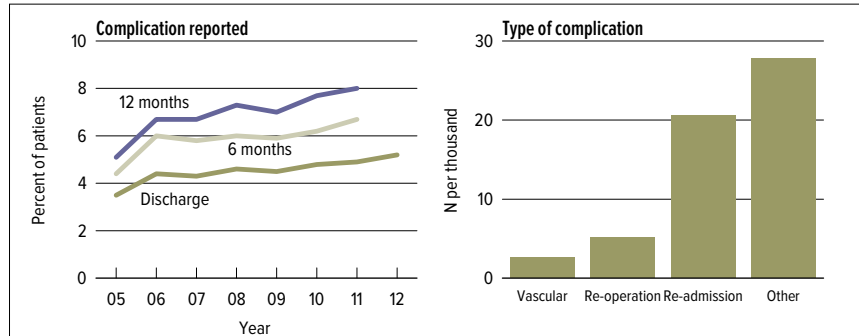
As reported on the OPTN Living Donor Registration form.

live donation



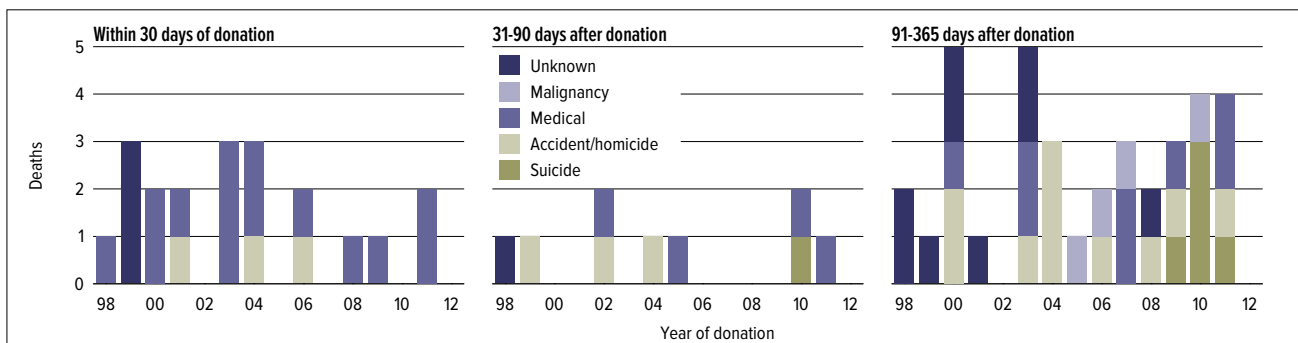
KI 3.4 Readmission to the hospital in the first 6 weeks, 6 months, and 1 year among living kidney donors

Cumulative readmission to the hospital. The six-week time point is recorded at the earliest of discharge or six weeks post-donation.



KI 3.5 Kidney complications among living kidney donors

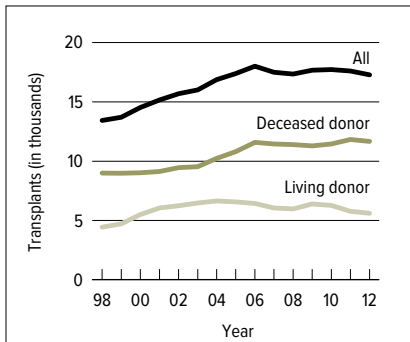
Complications reported on the Living Donor Registration and Living Donor Follow-up forms at each time point. Complications include readmission, re-operation, vascular complications, and other complications requiring intervention. Multiple complications may be reported at any time point. Type of discharge complication is shown among all living donors, 2005-2012.



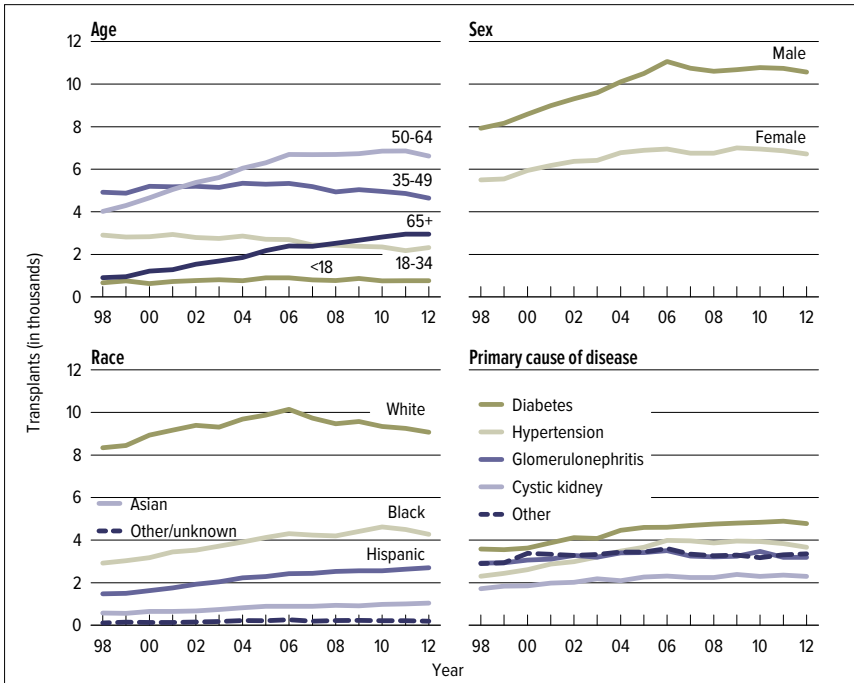
KI 3.6 Living kidney donor deaths

Living kidney donors. Deaths as reported to the OPTN or Social Security Administration. "Donation related" deaths are included in the "Medical" category.

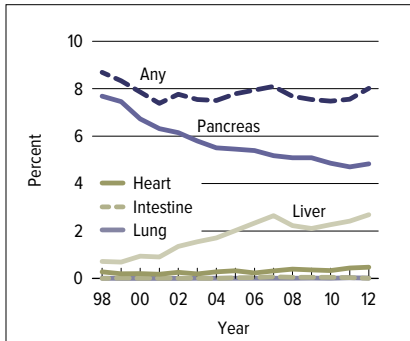
transplant



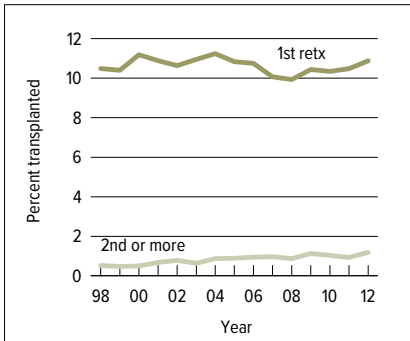
KI 4.1 Total kidney transplants
Patients receiving a transplant, including multi-organ transplants and pediatrics. Retransplants are counted.



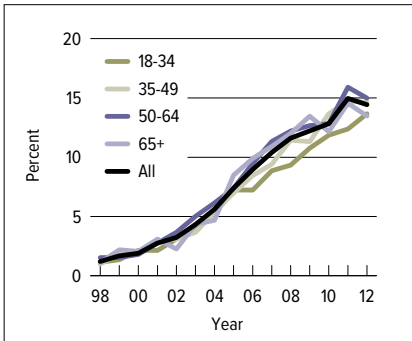
KI 4.2 Kidney transplants
Patients receiving a transplant, including multi-organ transplants and pediatrics. Retransplants are counted.



KI 4.3 Kidney transplants that were part of a multi-organ transplant
All adult patients receiving a deceased donor kidney transplant with at least one additional organ. A multi-organ transplant may include more than two different organs in total; if so, each non-kidney organ will be considered separately. Kidney transplants include living donor transplants.

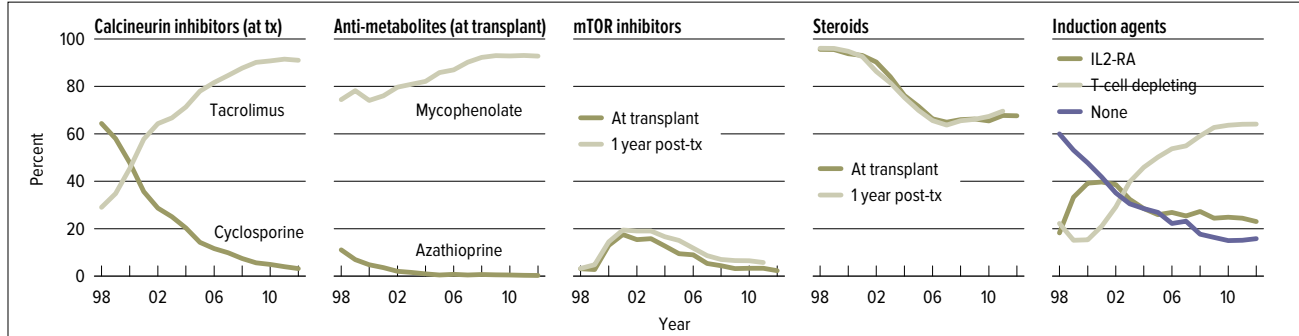


KI 4.4 Retransplants among adult kidney transplant recipients
Patients receiving a kidney retransplant (deceased or living donor) in the given year.



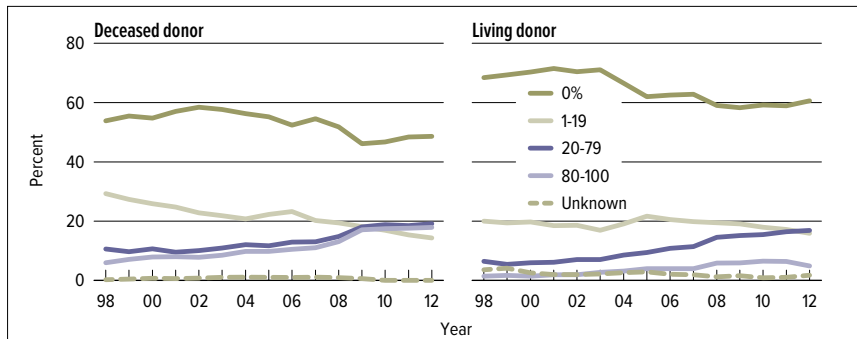
KI 4.5 Use of DCD kidneys among adult kidney-alone transplant recipients, by recipient age
Percent of deceased donor transplants using a DCD donor. DCD = donation after circulatory death.

transplant & donor-recipient matching



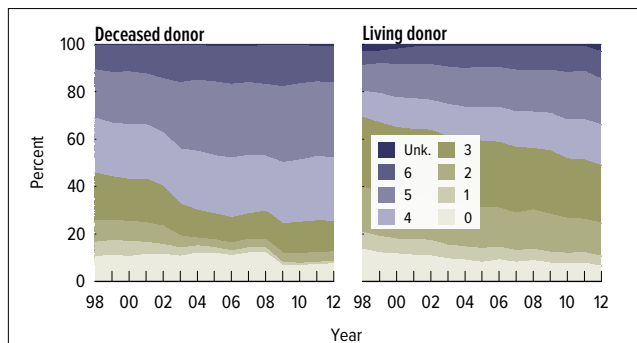
KI 4.7 Immunosuppression use in adult kidney transplant recipients

One-year post-transplant data limited to patients alive with graft function one year post-transplant. Mycophenolate group includes mycophenolate mofetil and mycophenolate sodium.



KI 5.1 PRA at time of kidney transplant in adult recipients

CPRA is used unconditionally from October 1, 2009 on. Between December 1, 2007 - October 1, 2009, CPRA is used if >0; otherwise, the maximum of the most recent PRA values pre-transplant is used. Prior to December 1, 2007, the maximum of the most recent PRA values pre-transplant is used unconditionally. Kidney-alone transplants only.



KI 5.2 Total HLA mismatches among adult kidney transplant recipients

Donor and recipient antigen matching is based on the OPTN's antigen values and split equivalences policy as of 2012.

donor-recipient matching

RECIPIENT	DECEASED DONOR				LIVING DONOR			
	Neg.	Pos.	Unk.	Total	Neg.	Pos.	Unk.	Total
Negative	12.4	18.6	0.1	31.1	23.2	15.8	2.0	41.0
Positive	24.0	43.1	0.2	67.3	20.5	34.4	2.7	57.6
Unknown	0.5	1.1	0.0	1.6	0.4	0.5	0.5	1.4
Total	37.0	62.8	0.3	100	44.2	50.7	5.1	100

KI 5.3 Adult kidney donor-recipient cytomegalovirus (CMV) serology matching, 2008–2012

Adult transplant cohort from 2008–2012. Donor serology is reported on the OPTN donor registration forms; recipient serology is reported on the OPTN recipient registration forms. Any evidence for a positive serology is taken to indicate that the person is positive for the given serology; if all fields are unknown, not done, or pending, the person is considered to be “unknown” for that serology; otherwise, serology is assumed negative.

RECIPIENT	DECEASED DONOR				LIVING DONOR			
	Neg.	Pos.	Unk.	Total	Neg.	Pos.	Unk.	Total
Negative	0.7	9.9	0.0	10.7	1.7	6.8	2.1	10.5
Positive	4.1	67.3	0.2	71.6	5.1	58.3	8.1	71.4
Unknown	1.0	16.6	0.1	17.7	0.4	3.8	13.8	18.1
Total	5.8	93.8	0.4	100	7.2	68.9	23.9	100

KI 5.4 Adult kidney donor-recipient Epstein-Barr virus (EBV) serology matching, 2008–2012

Adult transplant cohort from 2008–2012. Donor serology is reported on the OPTN donor registration forms; recipient serology is reported on the OPTN recipient registration forms. Any evidence for a positive serology is taken to indicate that the person is positive for the given serology; if all fields are unknown, not done, or pending, the person is considered to be “unknown” for that serology; otherwise, serology is assumed negative.

RECIPIENT	DECEASED DONOR				LIVING DONOR			
	Neg.	Pos.	Unk.	Total	Neg.	Pos.	Unk.	Total
Negative	75.4	2.7	0.0	78.2	71.4	1.4	8.1	81.0
Positive	7.7	0.7	0.0	8.5	3.5	0.4	0.6	4.4
Unknown	12.9	0.4	0.0	13.3	6.9	0.1	7.6	14.6
Total	96.0	3.9	0.1	100	81.8	1.9	16.3	100

KI 5.5 Adult kidney donor-recipient hepatitis B core antibody (HBcAb) serology matching, 2008–2012

Adult transplant cohort from 2008–2012. Donor serology is reported on the OPTN donor registration forms; recipient serology is reported on the OPTN recipient registration forms. Any evidence for a positive serology is taken to indicate that the person is positive for the given serology; if all fields are unknown, not done, or pending, the person is considered to be “unknown” for that serology; otherwise, serology is assumed negative.

RECIPIENT	DECEASED DONOR				LIVING DONOR			
	Neg.	Pos.	Unk.	Total	Neg.	Pos.	Unk.	Total
Negative	94.7	0.0	0.1	94.8	87.1	0.0	8.3	95.3
Positive	2.5	0.0	0.0	2.5	1.5	0.0	0.1	1.5
Unknown	2.7	0.0	0.0	2.7	2.3	0.0	0.9	3.1
Total	99.9	0.0	0.1	100	90.8	0.0	9.2	100

KI 5.6 Adult kidney donor-recipient hepatitis B surface antigen (HBsAg) serology matching, 2008–2012

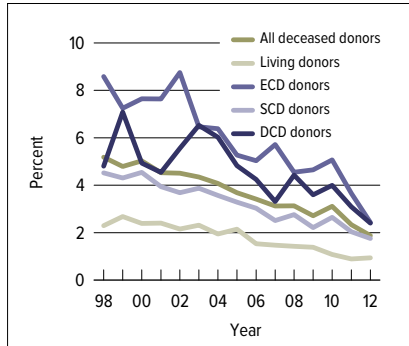
Adult transplant cohort from 2008–2012. Donor serology is reported on the OPTN donor registration forms; recipient serology is reported on the OPTN recipient registration forms. Any evidence for a positive serology is taken to indicate that the person is positive for the given serology; if all fields are unknown, not done, or pending, the person is considered to be “unknown” for that serology; otherwise, serology is assumed negative.

RECIPIENT	DECEASED DONOR				LIVING DONOR			
	Neg.	Pos.	Unk.	Total	Neg.	Pos.	Unk.	Total
Negative	90.5	0.2	0.0	90.7	87.3	0.2	6.8	94.2
Positive	4.3	2.0	0.0	6.3	2.1	0.0	0.2	2.3
Unknown	2.9	0.1	0.0	3.0	2.1	0.0	1.4	3.5
Total	97.7	2.3	0.0	100	91.5	0.2	8.3	100

KI 5.7 Adult kidney donor-recipient hepatitis C serology matching, 2008–2012

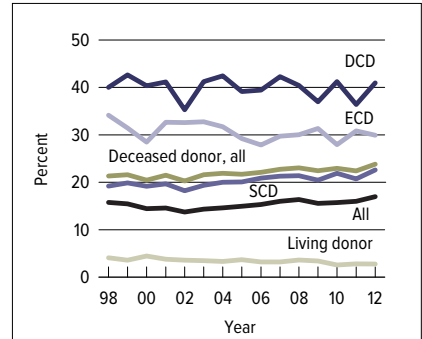
Adult transplant cohort from 2008–2012. Donor serology is reported on the OPTN donor registration forms; recipient serology is reported on the OPTN recipient registration forms. Any evidence for a positive serology is taken to indicate that the person is positive for the given serology; if all fields are unknown, not done, or pending, the person is considered to be “unknown” for that serology; otherwise, serology is assumed negative.

outcomes



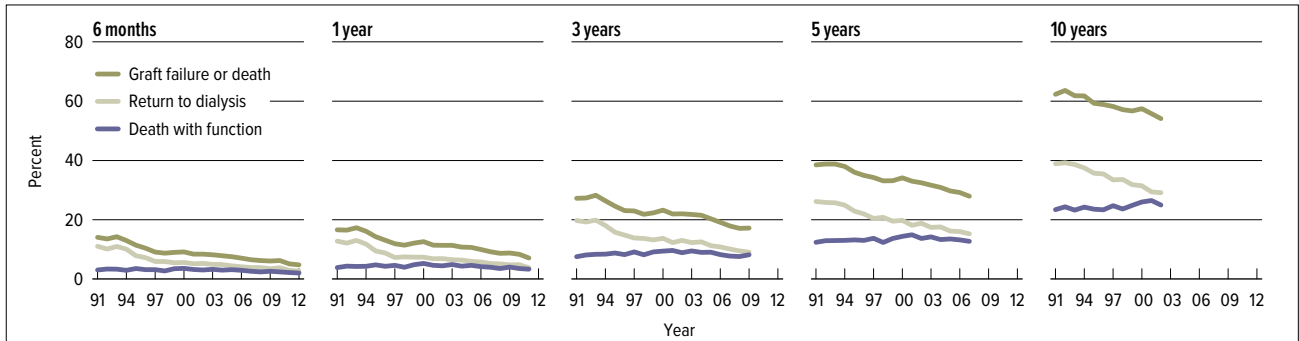
KI 6.1 Death-censored graft failure within 90 days among adult kidney transplant recipients

Limited to kidney-alone recipients. Retransplantation, graft failure, or return to dialysis within the first 90 days after transplant date. Graft failure due to death is not included. Graft failure dates are determined from multiple data sources, including the OPTN Transplant Recipient Registration and OPTN Transplant Recipient Follow-up. Transplants through September 30, 2012 are included to allow for sufficient follow-up.



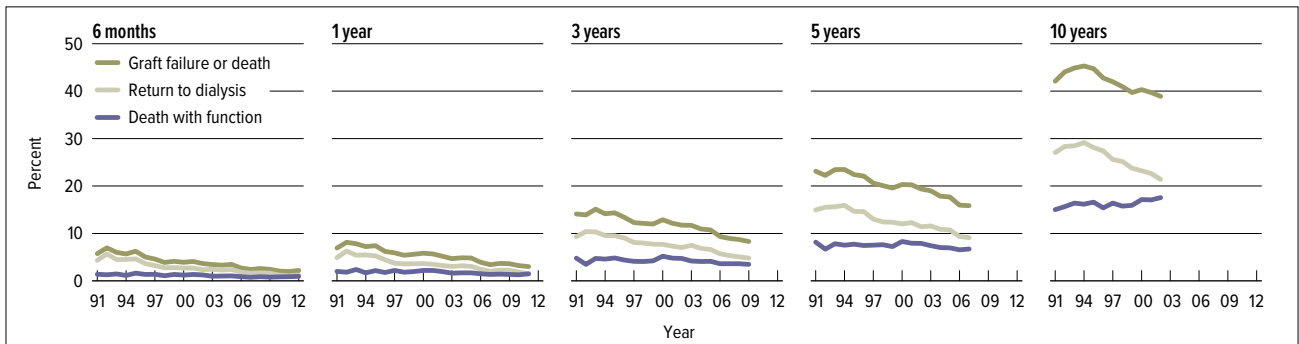
KI 6.2 Delayed graft function among adult kidney transplant recipients

Delayed graft function is defined as receiving dialysis within the first post-transplant week.



KI 6.3 Outcomes among adult kidney transplant recipients: deceased donor

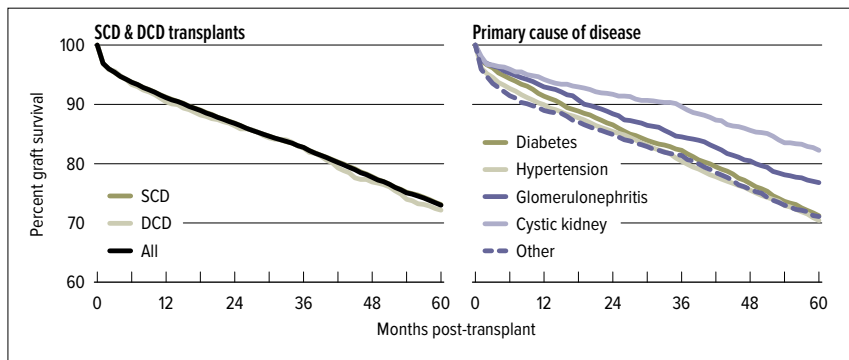
Percent for each outcome is unadjusted, computed using Kaplan-Meier competing risk methods. Death with function defined as no graft failure prior to death; return to dialysis defined as graft failure preceding death.



KI 6.4 Outcomes among adult kidney transplant recipients: living donor

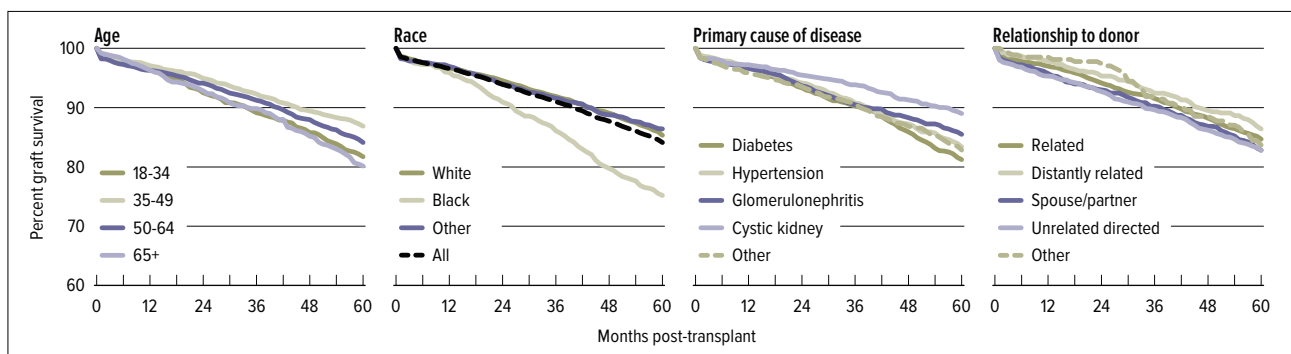
Percent for each outcome is unadjusted, computed using Kaplan-Meier competing risk methods. Death with function defined as no graft failure prior to death; return to dialysis defined as graft failure preceding death.

outcomes



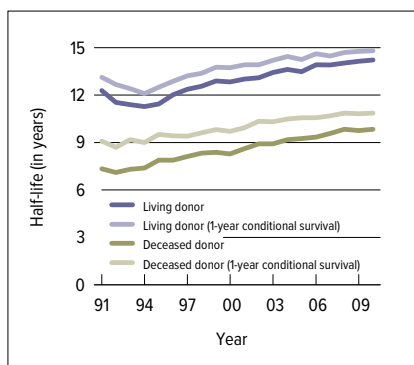
KI 6.5 Graft survival among adult kidney transplant recipients transplanted in 2007: deceased donors

Graft survival estimated using unadjusted Kaplan-Meier methods.



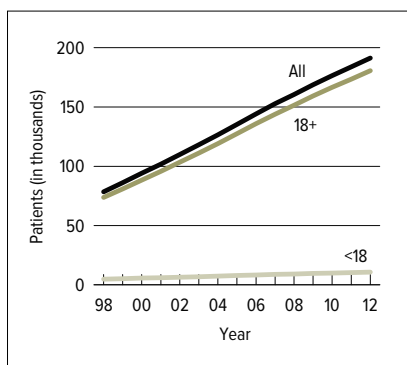
KI 6.6 Graft survival among adult kidney transplant recipients transplanted in 2007: living donors

Graft survival estimated using unadjusted Kaplan-Meier methods.



KI 6.7 Half-lives for adult kidney transplant recipients

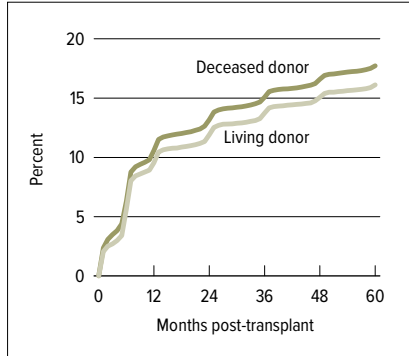
The half-life for a transplant cohort (e.g. 2009 kidney transplants) is the time point in follow-up at which 50% of the transplanted grafts have failed. A conditional half life for a transplant cohort is the same calculation but limited to those who survive with function at least 1 year post-transplant.



KI 6.8 Recipients alive & with a functioning kidney transplant on June 30 of the year

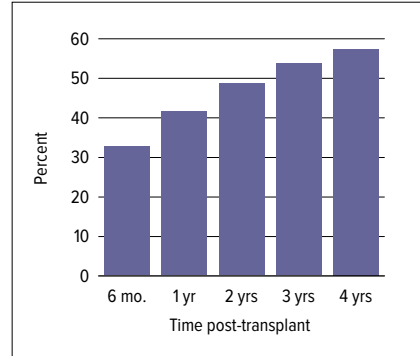
Transplants before June 30 of the year that are still functioning. Patients are assumed alive with function unless a death or graft failure is recorded. A recipient can experience a graft failure and drop from the cohort, then be retransplanted and re-enter the cohort. Age cut is based on age at transplant.

outcomes



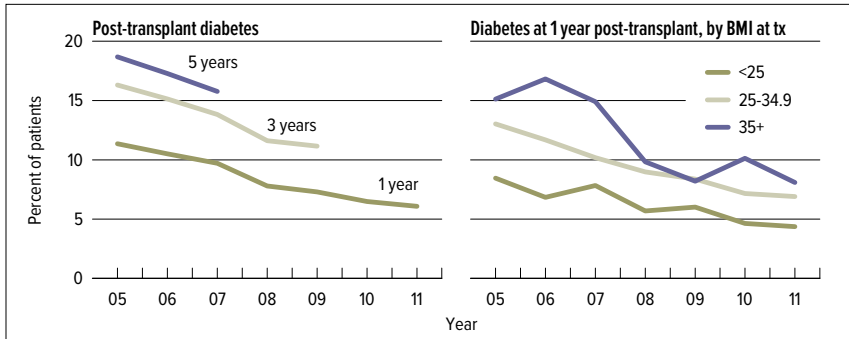
KI 6.9 Incidence of first acute rejection among adult patients receiving a kidney transplant in 2006–2010

Acute rejection defined as a record of acute or hyperacute rejection, or a record of an anti-rejection drug being administered on either the Transplant Recipient Registration form or the Transplant Recipient Follow-up form. Only the first rejection event is counted. Cumulative incidence, defined as the probability of acute rejection at any time prior to the given time, is estimated using Kaplan-Meier competing risk methods.



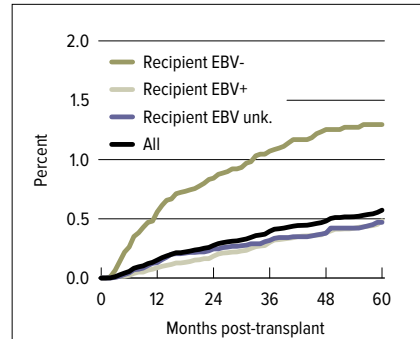
KI 6.10 Reported cumulative incidence of rehospitalizations among adult patients receiving a kidney transplant in 2007–2012

Cumulative rate of rehospitalization; hospitalization identified from follow-up form. Patients required to be alive with graft function at each time period, so denominators reduce over time.



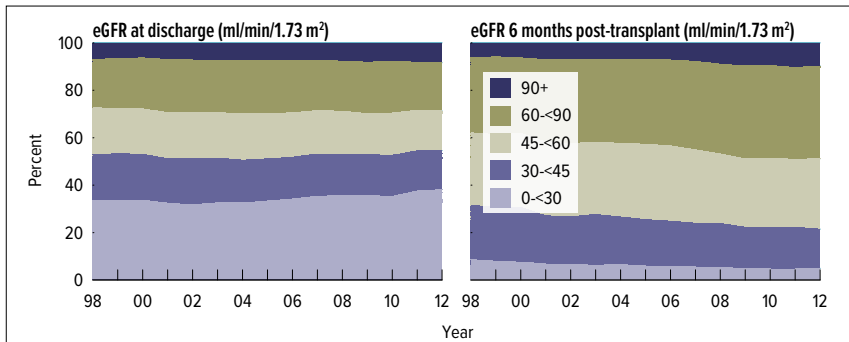
KI 6.11 Post-transplant diabetes among kidney transplant recipients

Percentage of adult deceased kidney recipients who develop diabetes post-transplant out of patients who are diabetes free at transplant.



KI 6.12 Incidence of PTLD among adult patients receiving a kidney transplant in 2006–2010, by recipient Epstein-Barr virus (EBV) status at transplant

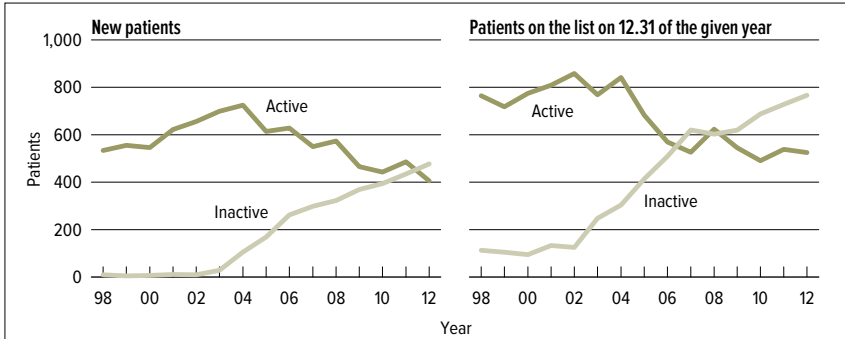
The cumulative incidence, is estimated using Kaplan-Meier competing risks methods. PTLD is identified as either a reported complication or cause of death on the Transplant Recipient Follow-up forms or on the Post-transplant Malignancy form as polymorphic PTLD, monomorphic PTLD, or Hodgkin's Disease. Only the earliest date of PTLD diagnosis is considered.



KI 6.13 Distribution of eGFR at discharge & 6 months post-transplant among adult kidney transplant recipients

GFR estimated using CKD-EPI equation, and computed for patients alive with graft function at the given time point.

pediatric transplant



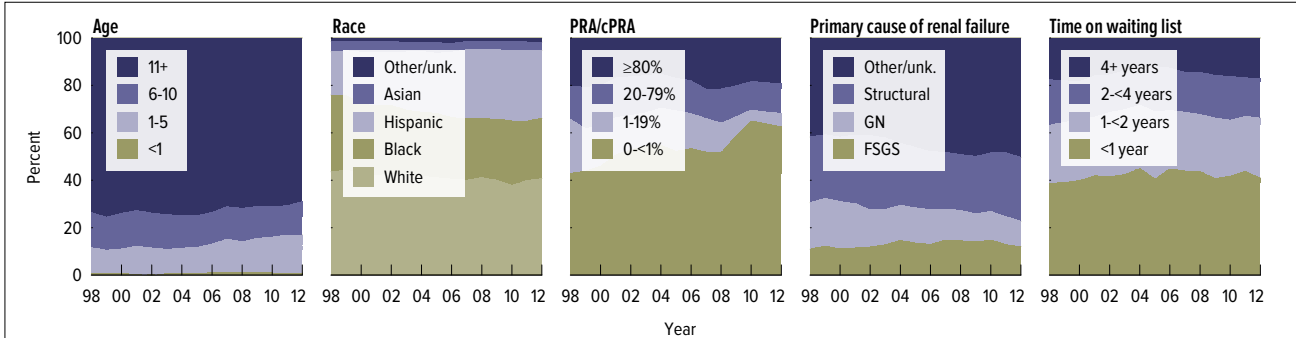
KI 7.1 Pediatric patients waiting for a kidney transplant

Patients waiting for a transplant. A "new patient" is one who first joins the list during the given year, without having listed in a previous year. However, if a patient has previously been on the list, has been removed for a transplant, and has relisted since that transplant, the patient is considered a "new patient." Patients concurrently listed at multiple centers are counted only once. Those with concurrent listings and active at any program are considered active; those inactive at all programs at which they are listed are considered inactive.

Reason for inactive status	Inactive w/i 7 days of listing		Active at listing, inact. on 12.31	
	N	%	N	%
Candidate work-up incomplete	342	64.3	38	19.8
Candidate choice	45	8.5	20	10.4
Too well	42	7.9	47	24.5
Too sick	35	6.6	48	25.0
Tx pending	24	4.5	2	1.0
Insurance issues	21	3.9	10	5.2
Weight inappropriate for tx	17	3.2	1	0.5
Medical non-compliance	4	0.8	15	7.8
Physician/surgeon unavailable	2	0.4	.	.
Unknown	.	.	5	2.6
Candidate could not be contacted	.	.	4	2.1
Inappropriate substance use	.	.	2	1.0

KI 7.2 Reasons for inactive status among pediatric kidney transplant listings, 2012

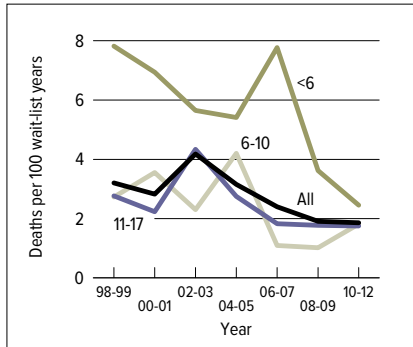
Reasons for inactive status of listings in 2012. Since patients can be concurrently listed at more than one center and have different reasons for going inactive at each center, each listing is counted separately.



KI 7.3 Distribution of pediatric patients waiting for a kidney transplant

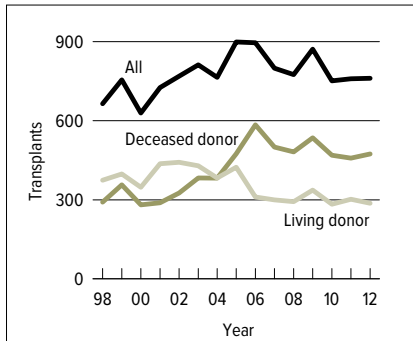
Patients waiting for a transplant any time in the given year. Age determined on the latest of listing date or January 1 of the given year. Concurrently listed patients are counted once. Primary cause of renal failure categorized according groups used by NAPRTCS. FSGS = focal segmental glomerulosclerosis. GN = glomerulonephritis.

pediatric transplant



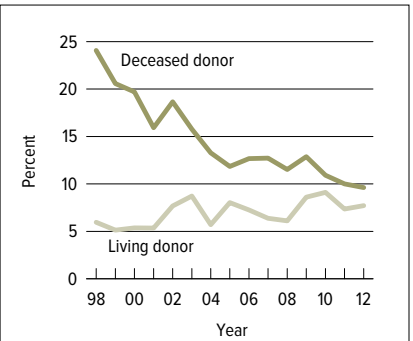
KI 7.9 Pre-transplant mortality rates among pediatric patients wait-listed for a kidney transplant, by age

Patients waiting for a transplant. Mortality rates are computed as the number of deaths per 100 patient-years of waiting time in the given interval. Waiting time is calculated as the total waiting time per age group in the interval. Only deaths that occur prior to removal from the waiting list are counted. Age is calculated on the latest of listing date or January 1 of the given period.



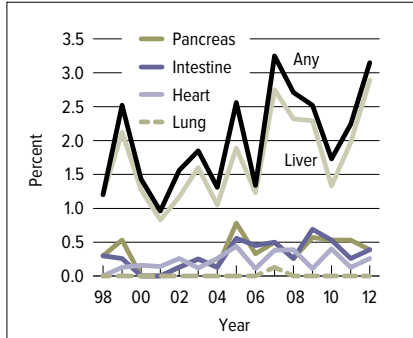
KI 7.10 Pediatric kidney transplants, by donor type

Patients receiving a kidney-alone or simultaneous kidney-pancreas transplant, by kidney donor type.



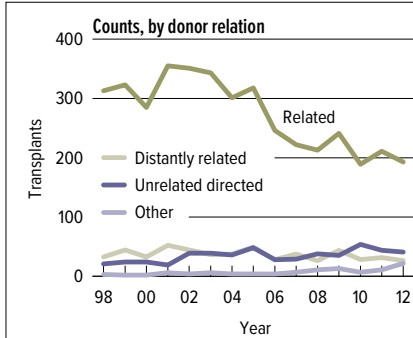
KI 7.11 Retransplants among pediatric kidney transplant recipients

Includes patients transplanted after age 17, but listed at age 17 or younger. Retransplanted patients include only those with a prior transplant of the same type.



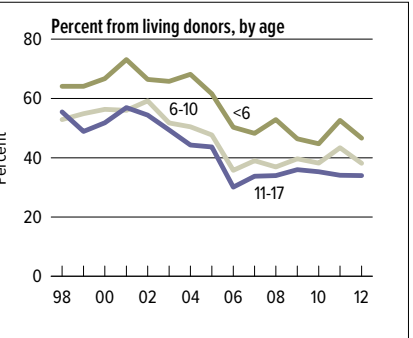
KI 7.12 Pediatric kidney transplants that were part of a multi-organ transplant

Patients receiving a deceased or living donor kidney transplant with at least one additional organ. A multi-organ transplant may include more than two different organs in total; if so, each non-kidney organ will be considered separately.



KI 7.13 Pediatric kidney transplants from living donors

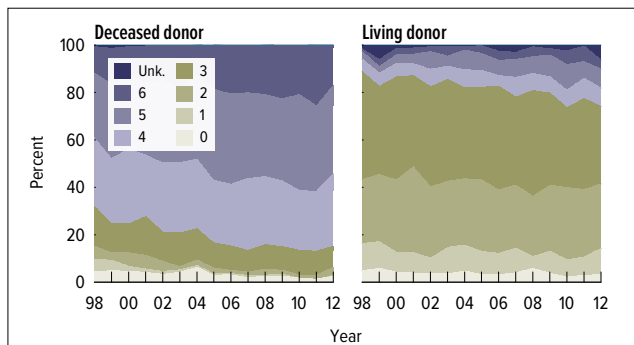
Relationship of living donor to recipient is as indicated on the Living Donor Registration form.



KI 7.13 Pediatric kidney transplants from living donors

Relationship of living donor to recipient is as indicated on the Living Donor Registration form.

pediatric transplant



KI 7.17 Total HLA mismatches among pediatric kidney transplant recipients

Donor and recipient antigen matching is based on the OPTN's antigen values and split equivalences policy as of 2012.

RECIPIENT	DECEASED DONOR				LIVING DONOR			
	Neg.	Pos.	Unk.	Total	Neg.	Pos.	Unk.	Total
Negative	4.6	36.1	0.3	41.0	6.9	36.2	8.0	51.1
Positive	5.7	45.9	0.1	51.6	3.7	32.6	4.8	41.1
Unknown	0.8	6.4	0.1	7.3	1.1	4.3	2.5	7.9
Total	11.1	88.4	0.5	100	11.7	73.1	15.2	100

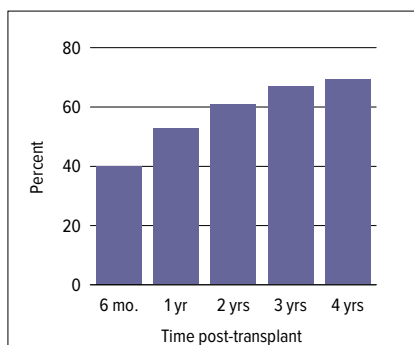
KI 7.18 Kidney donor-recipient Epstein-Barr virus (EBV) serology matching for pediatric transplant recipients, 2008–2012

Pediatric transplant cohort from 2008–2012. Donor EBV serology is reported on the OPTN Donor Registration forms; recipient EBV serology is reported on the OPTN Recipient Registration forms. Any evidence for a positive serology is taken to indicate that the person is positive for EBV; if all fields are unknown, not done, or pending the person is considered to be “unknown” for that serology; otherwise, serology is assumed negative.

RECIPIENT	DECEASED DONOR				LIVING DONOR			
	Neg.	Pos.	Unk.	Total	Neg.	Pos.	Unk.	Total
Negative	24.0	34.5	0.1	58.6	33.5	28.2	5.1	66.8
Positive	15.1	23.2	0.1	38.4	6.5	22.0	1.5	30.0
Unknown	1.1	1.8	0.0	3.0	1.3	1.7	0.2	3.2
Total	40.1	59.6	0.3	100	41.3	51.9	6.8	100

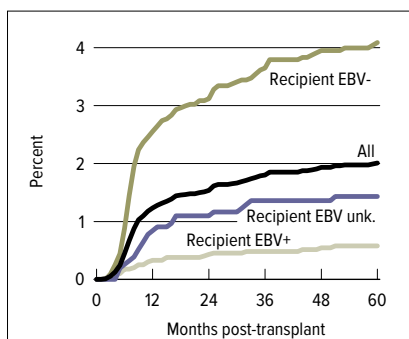
KI 7.19 Kidney donor-recipient cytomegalovirus (CMV) serology matching for pediatric transplant recipients, 2008–2012

Pediatric transplant cohort from 2008–2012. Donor CMV serology is reported on the OPTN Donor Registration forms; recipient CMV serology is reported on the OPTN Recipient Registration forms. Any evidence for a positive serology is taken to indicate that the person is positive for CMV; if all fields are unknown, not done, or pending the person is considered to be “unknown” for that serology; otherwise, serology is assumed negative.



KI 7.20 Reported cumulative incidence of rehospitalizations among pediatric patients receiving a kidney transplant in 2007–2012

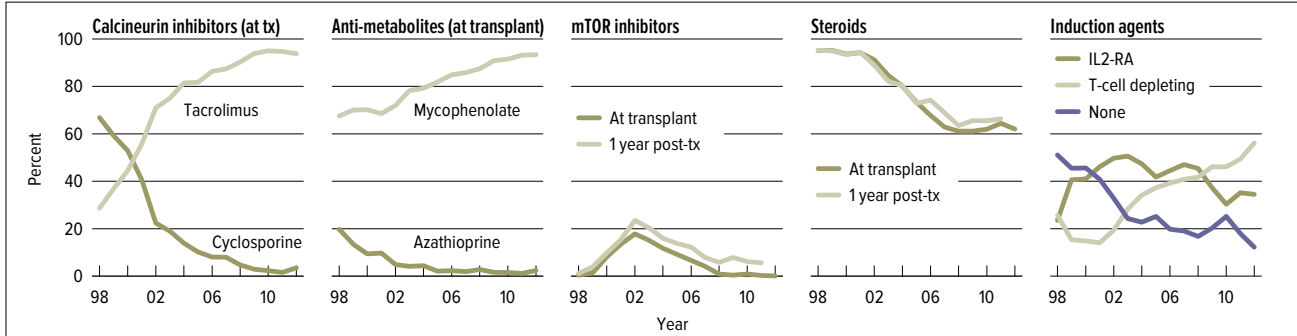
Cumulative incidence of rehospitalization post-transplant; hospitalization identified from the OPTN Transplant Recipient Follow-up form. Patients required to be alive with graft function at each time period, so denominators reduce over time.



KI 7.21 Incidence of PTLD among pediatric patients receiving a kidney transplant, 2000–2010, by recipient Epstein-Barr virus (EBV) status at transplant

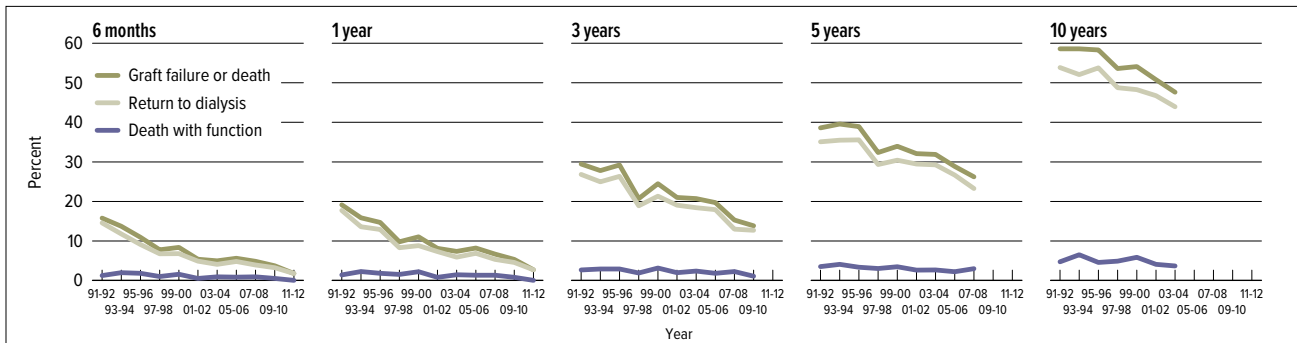
The cumulative incidence is estimated using Kaplan-Meier competing risks methods. PTLD is identified as either a reported complication or cause of death on the Transplant Recipient Follow-up forms or on the Post-transplant Malignancy form as polymorphic PTLD, monomorphic PTLD, or Hodgkin's Disease. Only the earliest date of PTLD diagnosis is considered.

pediatric transplant



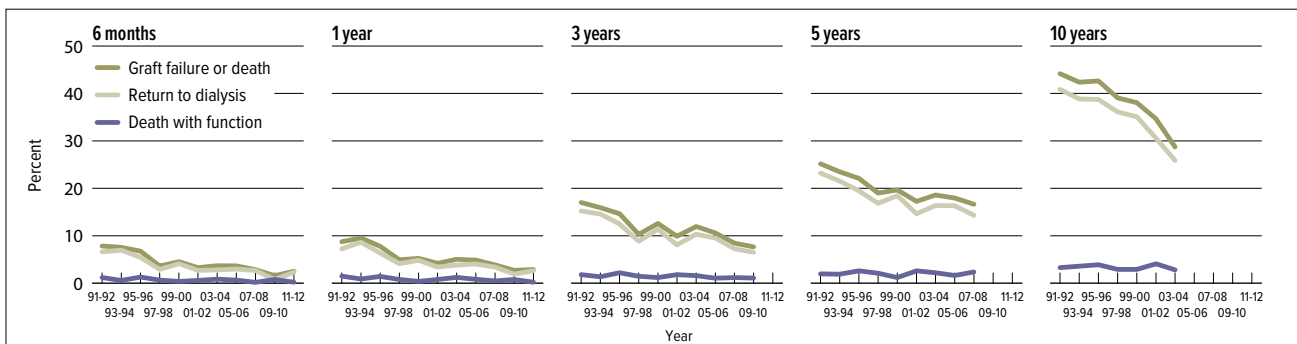
KI 7.22 Immunosuppression use in pediatric kidney transplant recipients

One-year post-transplant data limited to patients alive with graft function one year post-transplant. Mycophenolate group includes mycophenolate mofetil and mycophenolate sodium.



KI 7.23 Outcomes among pediatric kidney-alone transplant recipients: deceased donor

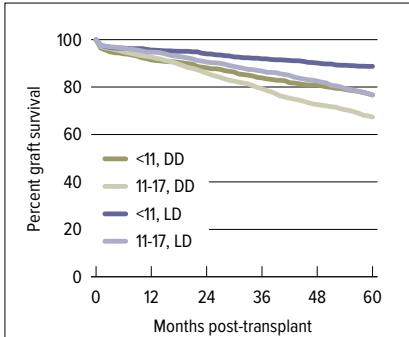
Percent for each outcome is unadjusted, computed using Kaplan-Meier competing risk methods. Death with function defined as no graft failure prior to death; return to dialysis defined as graft failure preceding death.



KI 7.24 Outcomes among pediatric kidney-alone transplant recipients: living donor

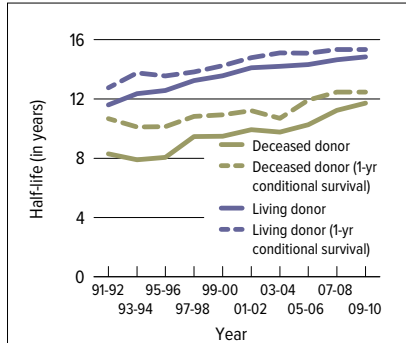
Percent for each outcome is unadjusted, computed using Kaplan-Meier competing risk methods. Death with function defined as no graft failure prior to death; return to dialysis defined as graft failure preceding death.

pediatric transplant



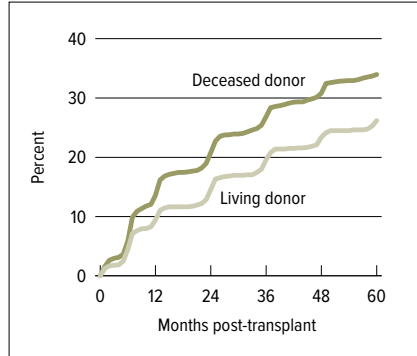
KI 7.25 Graft survival among pediatric kidney transplant recipients transplanted in 2003–2007, by age and donor type

Graft survival estimated using unadjusted Kaplan-Meier Methods. DD=deceased donor transplant; LD=living donor transplant.



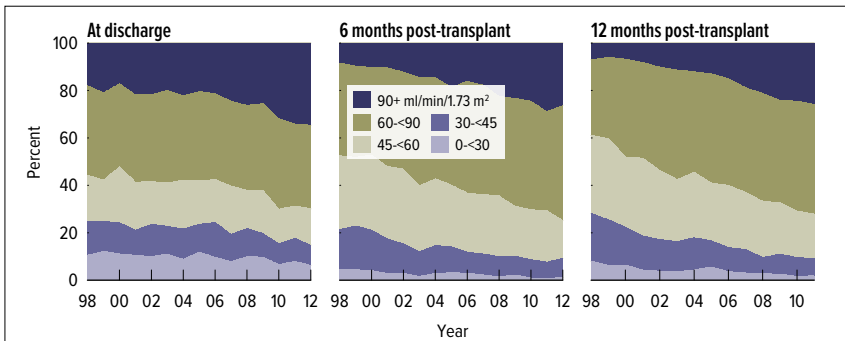
KI 7.26 Half-lives for pediatric kidney transplant recipients

The half-life for a transplant cohort (e.g. 2009 kidney transplants) is the time point at which 50% of the transplanted grafts have failed. A conditional half life for a transplant cohort is the same calculation but limited to those who survive with function at least 1 year post-transplant.



KI 7.27 Incidence of first acute rejection among pediatric patients receiving a kidney transplant in 2006–2011

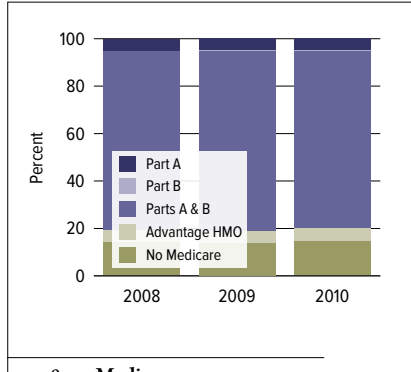
Acute rejection defined as a record of acute or hyperacute rejection, or a record of an anti-rejection drug being administered on either the Transplant Recipient Registration form or the Transplant Recipient Follow-up form. Only the first rejection event is counted. Cumulative incidence is estimated using Kaplan-Meier competing risk methods.



KI 7.28 Distribution of eGFR at discharge & at 6 & 12 months post-transplant among pediatric kidney-alone transplant recipients

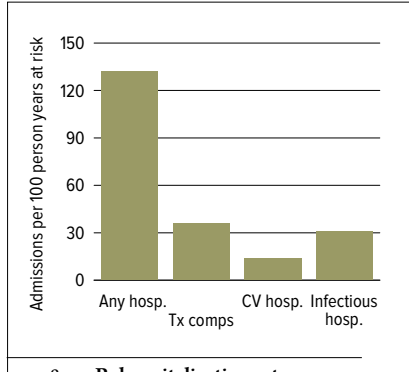
GFR estimated using the bedside Schwartz equation, and computed for patients alive with graft function at the given time point.

Medicare data



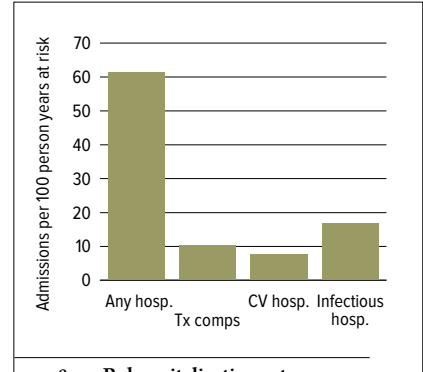
KI 8.1 Medicare coverage among kidney transplant recipients

Coverage at the time of transplant as identified by the Medicare Beneficiary Annual Summary supplied by CMS.



KI 8.2 Rehospitization rates among kidney transplant recipients in the first post-transplant year

Transplant recipients, 2008, with Medicare as the primary payer at transplant. Rehospitizations and reasons for rehospitization determined from Medicare claims. First year rates are based on rehospitizations occurring from initial discharge to one year later.



KI 8.3 Rehospitization rates among kidney transplant recipients in the second post-transplant year

Transplant recipients, 2008, with Medicare as the primary payer at transplant. Rehospitizations and reasons for rehospitization determined from Medicare claims. Second year rates are based on hospitalizations occurring from initial discharge+1 year to initial discharge+2 years.

Year 1 Cause of hospitalization	Percent of hospitalizations	Year 2 Cause of hospitalization	Percent of hospitalizations
Transplant complication	32.1	Transplant complication	21.8
Other infection	10.4	Other	9.2
Other	8.2	Other infection	9.1
Gastro-intestinal	6.5	Gastro-intestinal	7.5
Metabolic, endocrine, nutritional	5.2	Metabolic, endocrine, nutritional	7.0
Urinary tract infection	4.6	Urinary tract infection	5.8
Genito-urinary and breast	4.1	Respiratory infection	5.2
Electrolyte, acid-base & volume depletion	4.0	Bacteremia, viremia & septicemia	5.1
Bacteremia, viremia and septicemia	3.8	Genito-urinary and breast	4.4
Respiratory infection	3.4	CHF, fluid overload & cardiomyopathy	3.0

KI 8.4 Top ten causes of rehospitization among kidney recipients transplanted in 2008 with Medicare primary coverage

Transplant recipients, 2008, with Medicare as the primary payer at transplant. Reasons for rehospitization determined from Medicare claims, denominator for percentages includes only those re-hospitalized.

		# patients	Total costs		PPPY costs	
			Part A	Part B	Part A	Part B
	All patients	18,837	1,135,310,769	357,401,120	63,432	19,969
Age	0-11	229	22,220,892	4,537,430	100,209	20,462
	12-17	316	22,649,454	5,922,016	74,961	19,600
	18-34	2,439	133,740,792	47,698,093	56,890	20,289
	35-49	5,167	296,938,347	99,833,315	60,064	20,194
	50-64	6,923	426,677,980	128,799,267	65,013	19,625
	65+	3,763	233,083,304	70,610,999	66,280	20,079
Sex	Male	11,528	696,322,787	217,596,282	63,541	19,856
	Female	7,309	438,987,983	139,804,838	63,260	20,147
Race	White	8,952	535,165,623	163,295,568	62,882	19,187
	Black	5,758	372,705,121	115,979,706	68,676	21,371
	Hispanic	2,857	160,062,784	56,465,170	58,282	20,560
	Asian/Pac. Isl.	972	51,693,735	16,847,714	55,624	18,129
	Other/unk.	298	15,683,507	4,812,962	55,075	16,901
Primary cause of disease	Diabetes	5,423	363,975,149	112,281,926	71,489	22,054
	Hypertension	5,109	292,187,964	96,489,598	60,346	19,928
	GN	3,123	161,068,392	54,527,386	53,566	18,134
	Cystic kidney dis.	1,847	97,726,796	31,525,000	54,614	17,618
	Other/unknown	3,335	220,352,468	62,577,210	69,545	19,750

ki 8.5 Total and per-person per-year (PPPY) Medicare costs (\$) among kidney transplant recipients in the first post-transplant year

Costs among recipients transplanted in 2008 and 2009 who had Medicare as the primary payer at the time of transplant. First year costs include the transplant hospitalization. Costs incurred after a transplant failure are excluded.

		# patients	Total costs		PPPY costs	
			Part A	Part B	Part A	Part B
	All patients	8,321	117,269,980	90,690,952	14,427	11,157
Age	0-11	95	1,602,410	1,028,434	17,018	10,922
	12-17	133	2,921,075	1,393,174	22,635	10,795
	18-34	1,121	14,389,113	12,561,407	13,142	11,472
	35-49	2,322	28,738,475	25,871,033	12,618	11,359
	50-64	3,015	43,868,019	31,919,425	14,939	10,870
	65+	1,635	25,750,888	17,917,479	16,131	11,224
Sex	Male	5,101	69,286,158	54,131,145	13,906	10,865
	Female	3,220	47,983,822	36,559,807	15,251	11,620
Race	White	3,959	55,630,442	41,054,375	14,329	10,575
	Black	2,492	38,422,595	29,305,341	15,979	12,187
	Hispanic	1,290	16,827,913	14,957,845	13,219	11,750
	Asian/Pac. Isl.	452	4,780,270	4,303,670	10,772	9,698
	Other/unk.	128	1,608,760	1,069,721	12,873	8,560
Primary cause of disease	Diabetes	2,377	42,539,049	29,203,910	18,413	12,641
	Hypertension	2,262	30,843,121	24,480,898	13,953	11,074
	GN	1,444	16,258,100	14,044,215	11,504	9,937
	Cystic kidney dis.	769	8,039,356	7,313,759	10,667	9,704
	Other/unknown	1,469	19,590,354	15,648,170	13,597	10,861

ki 8.6 Total and per-person per-year (PPPY) Medicare costs (\$) among kidney transplant recipients in the second post-transplant year

Costs among recipients transplanted in 2008 who had Medicare as the primary payer at the time of transplant. The second post-transplant year runs from 366 to 730 days after transplant. Costs incurred after a transplant failure are excluded.

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OPTN/SRTR 2012 Annual Data Report:

pancreas

ABSTRACT The number of pancreas transplants has decreased over the past decade, most notably numbers of pancreas after kidney (PAK) and pancreas transplant alone (PTA) procedures. This decrease may be mitigated in the future when changes to national pancreas allocation policy approved by the Organ Procurement and Transplantation Network Board of Directors in 2010 are implemented. The new policy will combine waiting lists for PAK, PTA, and simultaneous pancreas-kidney (SPK) transplants, and give equal priority to candidates for all three procedures. This policy change may also eliminate geographic variation in waiting times caused by geographic differences in allocation policy. Deceased donor pancreas donation rates have been declining since 2005, and the donation rate remains low. The outcomes of pancreas grafts are difficult to describe due to lack of a uniform definition of graft failure in the transplant community. However, long-term survival is better for SPK versus PAK and PTA transplants. This may represent the difficulty of detecting rejection in the absence of a simultaneously transplanted kidney. The challenges of pancreas transplant are reflected in high rates of rehospitalization, most occurring within the first 6 months posttransplant. Pancreas transplant is associated with higher incidence of rejection compared with kidney transplant.

KEY WORDS Pancreas after kidney transplant, pancreas allocation policy, pancreas transplant alone, simultaneous pancreas-kidney transplant.

There are so many things I want to do... Just being able to go for a walk or a run ... I plan on traveling and even going skiing for the first time. What I really want is to someday have a family... My list just goes on and on.

waiting for a double lung transplant

Introduction

The number of pancreas transplants has decreased over the past decade. In light of this decline, this chapter describes changes in the waiting list, pancreas transplants, and post-transplant outcomes. The decreased numbers of pancreas transplants may be partly attributable to improved insulin delivery systems, concerns about outcomes after solitary pancreas transplant [1], and islet transplant. The most notable decreases in numbers of pancreas transplants occurred for pancreas after kidney (PAK) and pancreas transplant alone (PTA) procedures.

The decrease in PAK and PTA transplants may be mitigated in the future when changes in national policy are implemented by the Organ Procurement and Transplantation Network (OPTN); changes were approved by the OPTN Board of Directors in November 2010. A combined pancreas waiting list for simultaneous pancreas-kidney (SPK) transplants and solitary pancreas transplants (PAK and PTA) will give equal priority to candidates for all three procedures within locality, human leukocyte antigen (HLA) mismatch status, calculated panel reactive antibody (CPRA) status, and waiting time duration.

A detailed analysis of pancreas transplant trends over the past decade is presented in the following sections.

Waiting List

The number of new candidates on the pancreas waiting list showed an increasing trend from 1998 until 2000, after which it decreased steadily until 2011, when only 1710 candidates joined the waiting list. A slight increase occurred in 2012 when 1738 candidates joined the waiting list (Figure 1.1). However, the increase was limited to new SPK candidates, while new PAK and PTA listings continued to decline. The number of prevalent active candidates, determined at the end of each calendar year, declined since its peak in 2002 to a low of 1311 active candidates in 2012, slightly less than the 1354 active can-

didates in 2011. The total number of candidates (active and inactive) at the end of each calendar year mirrored the trend among active candidates; counts continued to decline from 2011 to 2012, from 3174 to 3072 (Figure 1.1).

The proportion of older candidates (aged 50-64 years) gradually increased over the past decade, with a corresponding decrease in the proportion of younger candidates (aged 18-34 years) (Figure 1.2). The percentage of white candidates (66.9% in 2012) decreased over the past decade, with a corresponding increase in the percentage of black (18.7% in 2012) and Hispanic (11.5% in 2012) candidates. The percentage of candidates reported to have type 2 diabetes remained stable (8.2% in 2012). The percentage of obese candidates (body mass index [BMI] > 30 kg/m²) gradually increased, in keeping with national trends in the general population. Although relatively fewer candidates are registered on the waiting list, time on the waiting list gradually increased over the past decade. Whether this was due to more restrictive acceptance criteria or other reasons is yet to be determined (Figure 1.2).

When waiting time was limited to active time only, transplant rates generally increased from 2003 to 2010. Since 2010, these rates have stabilized or decreased slightly, to 73 transplants per 100 active wait-list years in 2012 (PTA, 82 transplants per 100 wait-list years; SPK, 73; PAK, 71) (Figure 1.4). Including inactive time on the waiting list in the calculations causes all transplant rates to decrease dramatically from 1999 to 2012 (data not shown).

In 2012, 89 living donor kidney transplants were performed in SPK wait-listed candidates, down from 138 in 2010 (Figure 1.6). This is in keeping with a decline in living donor kidney transplants from 2010 to 2012 (see Kidney chapter).

Outcomes for candidates on the waiting list over a 3-year follow-up period (from the time of listing) are shown in Figure 1.7. Median time to transplant for active candidates listed in 2010-2011 was 19.1 months for PTA and 16.2 months for

SPK. The median time to transplant for PAK candidates listed in 2010-2011 cannot be estimated since less than 50% underwent transplant by December 31, 2012. The most recent estimate available for PAKs was 36.9 months, for candidates listed in 2008-2009. The disparity between SPK and PTA versus PAK transplant rates suggests significant differences between these candidate groups. Waiting times for SPK, PAK, and PTA vary by donation service area (DSA) (Figure 1.5). In six DSAs, no transplant program performed pancreas transplants in 2011-2012. Currently, OPTN policy allows for local organ procurement organizations (OPOs) to use their discretion in prioritizing SPK or solitary pancreas (PTA or PAK) offers; this lack of national policy may contribute to the overall geographic variation. A universal SPK and pancreas-alone allocation policy approved by OPTN in November 2010 is pending implementation. The combined pancreas waiting list will treat SPK, PAK, and PTA candidates equally. This may eliminate variation caused by geographic differences in allocation policy.

The 2012 pretransplant mortality rate for candidates wait-listed for pancreas transplant was 5.3 deaths per 100 wait-list years (Figure 1.10), lower than for candidates wait-listed for kidney transplant. Mortality has been consistently higher among SPK candidates (6.9 patient deaths per 100 wait-list years in 2012, versus 2.0 and 2.1 for PTA and PAK, respectively).

Donation

Deceased donor pancreas donation rates have been decreasing steadily since 2005. Only the pancreata that were recovered for the purpose of pancreas transplant (not islet transplant) were included in this analysis. In 2011, the overall rate reached a low of 2.2 donors aged younger than 75 years per 1000 deaths (Figure 2.1). The donation rate for donors aged 15 to 34 years decreased in 2011, to 14 donors per 1000 deaths compared with 15 in 2010. Unadjusted geographic heterogeneity in donation rates is substantial (Figure 2.2). The pancreas discard rate per

donor varies significantly with donor age. In 2011, pancreata were discarded from 26.2% of all pancreas donors (Figure 2.3). However, the discard rate is based on pancreata discarded after recovery; it does not take into account pancreata never recovered due to lack of suitability.

The pancreas donor risk index [2] steadily decreased over the past decade. The donor-specific components of the pancreas donor risk index show that frequency of most risk factors declined over the past decade, except that use of pancreata from black donors increased (Figure 2.4). Procurement of pancreata from donation after circulatory death (DCD) declined from its peak in 2009; DCD donors accounted for 3.1% of procured pancreata in 2012, comparable to the percentage in 2004 (Figure 2.5). Head trauma was the most common cause of death for pancreas donors. Anoxic brain injury as a cause of death has steadily increased, reaching 21.0% of donors in 2012 (Figure 2.6).

Transplant

The number of pancreas transplants decreased every year since 2004; 1043 pancreas transplants were performed in 2012 and 1082 in 2011 (Figure 3.1). The greatest percentage decrease was for PAK, followed by SPK and PTA. The 2012 count of pancreas transplants includes both adult and pediatric recipients (Figure 3.1), in contrast to the counts reported in the 2011 Annual Data Report.

Compared with 2004, the decrease in transplant numbers was greatest in the most prevalent demographic groups: recipients aged 35 to 49 years, recipients of white race, recipients with BMI 18.5 to 24.9 kg/m² and recipients with type 1 diabetes (Figure 3.2). In contrast, the number of pancreas transplants performed as part of a multi-organ transplant has increased since 2004. The most common multi-organ transplant was kidney-pancreas transplant, which accounted for 78.9% of all pancreas transplants in 2012. Overall, 81.0% of pancreas

transplants in 2012 were part of a multi-organ transplant (Figure 3.3).

Compared with 2004, the number of pancreas retransplants continued to decline. In 2012, only 6.0% of pancreas transplants in adult recipients were retransplants (Figure 3.4). Use of DCD donors decreased in 2010-2012 to 2.62%, versus 2.95% in 2008-2009. Characteristics of patients undergoing pancreas transplant in 2012 are summarized in Figure 3.6. In 2012, private insurance covered 43.7% of all pancreas transplants and Medicare covered 49.9%. Retransplants were most common among PAK recipients, constituting 33.1% of all PAK transplants (Figure 3.6).

Donor-Recipient Matching

The percentage of unsensitized recipients (0% PRA) has gradually decreased; 60.2% were unsensitized in 2012 and 62.4% in 2011, versus 77.4% in 1998 (Figure 4.1).

HLA matching for pancreas transplants showed that the percentages of highly mismatched transplants (5 or 6 mismatches) were 43.2% of PTA, 55.9% of SPK, and 52.1 of PAK in 2012 (Figure 4.2). Donor-recipient virology data were analyzed for 2008-2012; 26.9% of all transplants were at high-risk for cytomegalovirus disease (donor positive, recipient negative) (Figure 4.3) and 13.4% were at high risk for Epstein-Barr virus (EBV)-related complications (donor positive, recipient negative) (Figure 4.4).

Donors positive for hepatitis B virus and hepatitis C virus were extremely rare (Figures 4.5-4.7).

Outcomes

The outcomes of pancreas grafts are difficult to describe due to lack of a uniform definition of graft failure in the transplant community. Some centers report a graft failure upon resumption of any diabetes medication, whereas other centers do not report a graft failure unless diabetes medications are resumed

at levels similar to or in excess of pretransplant levels. Furthermore, the definition used by any given transplant center is not publicly known. This variation led the OPTN Pancreas Transplantation Committee to attempt to standardize the definition of pancreas graft failure for future use; this work is ongoing.

Keeping this limitation in mind, unadjusted graft survival at 5 years was 53% for PTA and 65% for PAK transplants; 5-year survival of the pancreas graft in SPK transplants was 73% for transplants performed in 2007 (Figure 5.5). The better long-term survival for SPK versus PAK and PTA may represent the difficulty of detecting rejection in the absence of a simultaneously transplanted kidney. Detection of an early rejection episode is more likely after SPK transplant, since elevated serum creatinine is a marker that triggers further work-up for rejection. Unfortunately, after PTA and PAK transplants, such a surrogate marker for pancreas rejection is unavailable, and pancreas biopsies are not routinely performed at all centers.

The long-term kidney graft survival rate for SPK recipients continues to improve (Figure 5.2). For SPK transplants performed in 2007, unadjusted 5-year kidney graft failure declined to 20.3% (Figure 5.4). The excellent long-term results for kidneys transplanted as part of an SPK procedure are in part related to the highly selected nature of SPK deceased donors.

Kidney graft failure or death after a PAK transplant steadily decreased. Five-year kidney graft failure after a pancreas transplant was 20.2% (Figure 5.4, upper panel). Thus, the number of recipients alive with a functioning pancreas allograft continued to rise over the past decade and exceeded 13,000 in 2012 (Figure 5.7).

The challenges of pancreas transplant are reflected in the very high rates of rehospitalization among adults who underwent a pancreas transplant in 2007-2012. Most rehospitalizations occurred within the first 6 months posttransplant (Figure 5.9). Pancreas transplant is associated with higher incidence of rejection compared with kidney transplant,

reflecting the relatively high immunogenicity of the pancreas allograft (Figure 5.8). Figure 5.8 also shows that incidence of rejection is highest for PTA recipients. This relates in part to their healthier overall state and ability to mount a strong immune response as compared with the uremic SPK recipients. The higher immunosuppression requirements associated with PTA are reflected in the markedly higher incidence of posttransplant lymphoproliferative disorder (PTLD) in PTA recipients (Figure 5.10). PTLD incidence is higher in all EBV-negative recipients; 5.0% of EBV-negative PTA recipients who underwent transplant in 2006-2010 were diagnosed with PTLD within 12 months of pancreas transplant, versus 2.0% of SPK and 1.1% of PAK recipients.

Economics

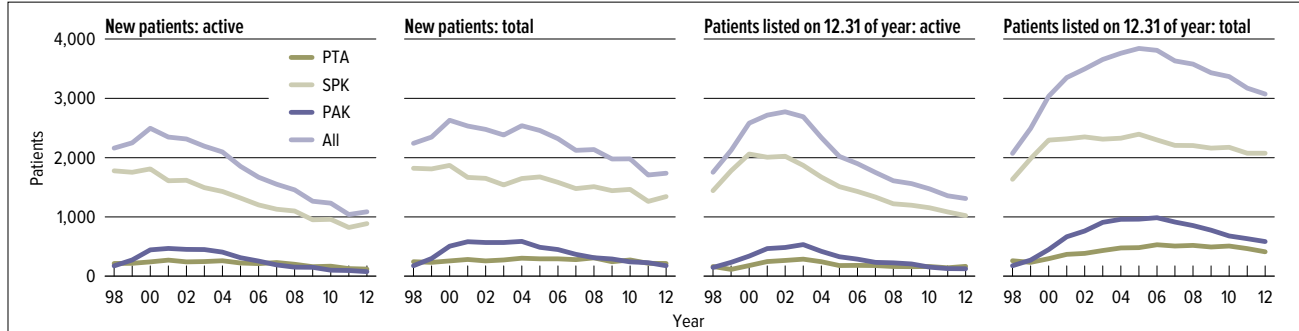
The economics of pancreas transplant are primarily driven by two factors: first, the predominance of simultaneous transplant of both a pancreas and a kidney into diabetic end-stage renal disease patients, and second, the tendency toward selection of higher-quality kidneys and lower-risk patients compared with kidney transplant without a pancreas. Average reimbursement for pancreas recipients with primary Medicare coverage from transplant through 1-year posttransplant was \$98,440 for Part A and \$25,163 for Part B (Figure 6.5), totaling \$123,602. For comparison, Medicare reimbursement for diabetic recipients of kidney transplant without a pancreas was similar, \$71,489 for Part A and \$22,054 for Part B, totaling \$93,543 (Figure 8.5, Kidney chapter). Rehospitalization rates were remarkably lower in pancreas transplant recipients than in recipients of kidney transplant without a pancreas (Figures 6.2 and 6.3; Figures 8.2 and 8.3, Kidney chapter), at approximately one-third the frequency in the first year and one-fourth in the second. Annual costs following the first year were dramatically lower for Medicare Parts A and B, averaging \$16,842 and \$14,335, respectively, and totaling \$31,177 (Figure

6.6); cost is expected to remain stable in later years. Additional costs are not accounted for here, including reimbursement to hospitals for the transplant portion of the Medicare Cost Report and Medicare Part D costs. Including estimates for these brings the average Medicare cost to approximately \$230,000 in the first year posttransplant and approximately \$35,000 in subsequent years. Pancreas transplant recipients accounted for 5% of all Medicare Parts A and B expenditures following solid organ transplant, or \$224 million, \$28,681 per patient, in 2010 (Figure 6.7).

References

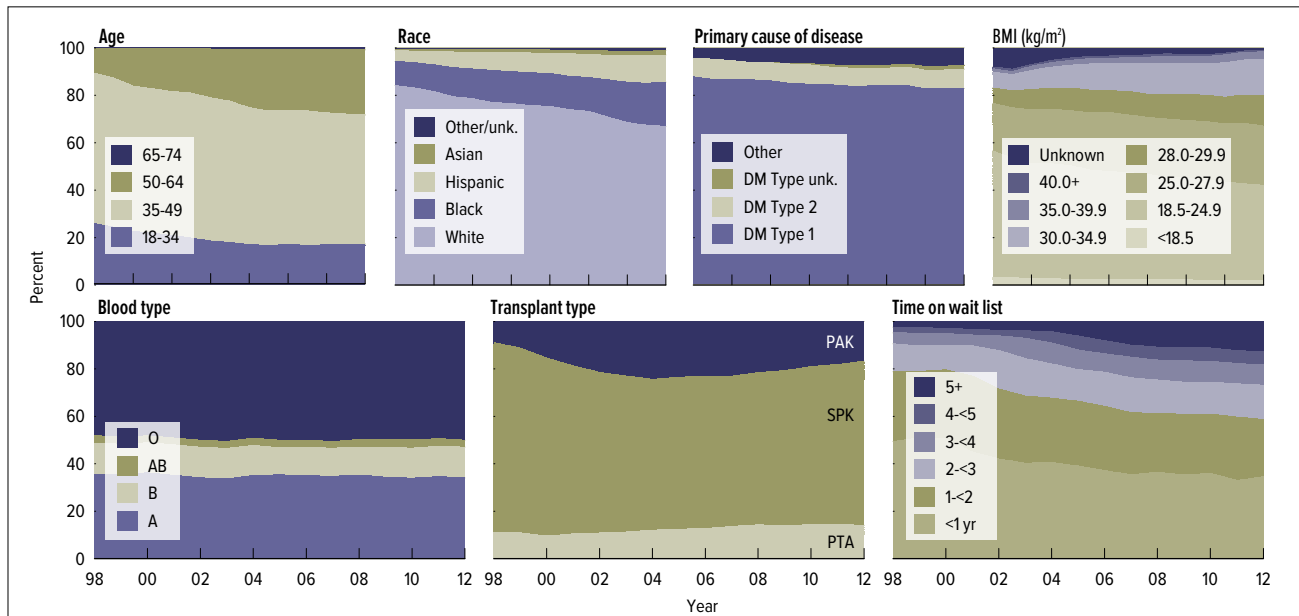
1. Venstrom J, McBride M, Rother K, Hirshberg B, Orchard T, Harlan D. Survival after pancreas transplantation in patients with diabetes and preserved kidney function. *JAMA* 2003; 290: 2817-2823.
2. Axelrod DA, Sung RS, Meyer KH, Wolfe RA, Kaufman DB. Systematic evaluation of pancreas allograft quality, outcomes and geographic variation in utilization. *Am J Transplant* 2010; 10: 837-845.

wait list



PA 1.1 Adult patients waiting for a pancreas transplant

Patients waiting for a transplant. A “new patient” is one who first joins one of the three lists during the given year, without having listed in a previous year. However, if a patient has previously been on the list, has been removed for a transplant, and has relisted since that transplant, the patient is considered a “new patient.” Patients concurrently listed at multiple centers or on more than one list are counted only once. Those with concurrent listings and active at any program are considered active; those inactive at all programs at which they are listed are considered inactive. Death data were available only through 2011.



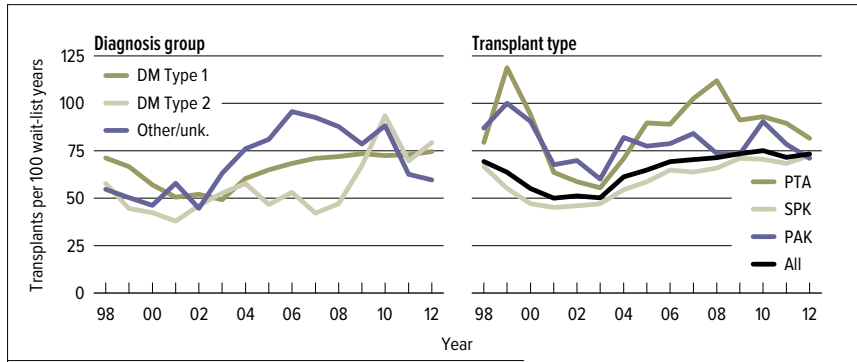
PA 1.2 Distribution of adult patients waiting for a pancreas transplant

Patients waiting for a transplant any time in the given year. Age determined on the earliest of listing date or December 31 of the given year. Concurrently listed patients are counted once.

Time on wait list

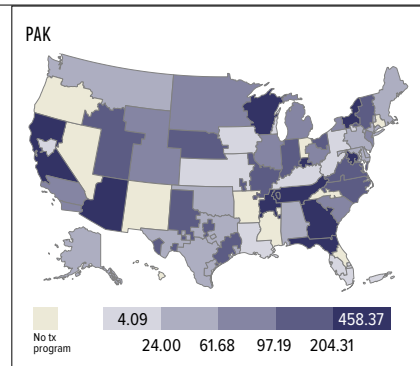
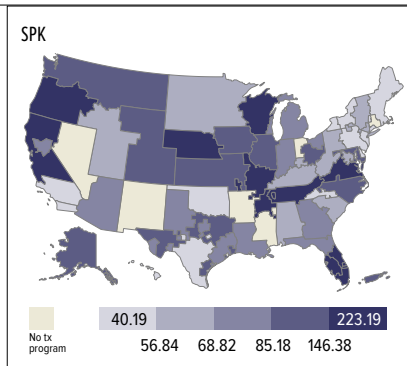
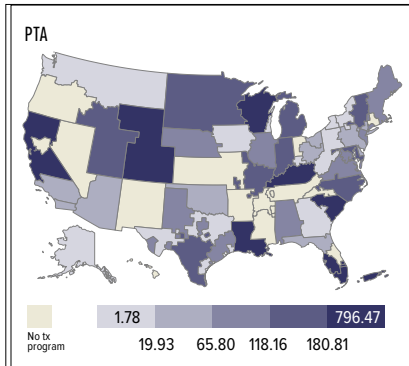
- 5+
- 4-5
- 3-4
- 2-3
- 1-2
- <1 yr

wait list



PA 1.4 Deceased donor pancreas transplant rates among active adult waiting list candidates

Transplant rates are computed as the number of deceased donor transplants per 100 patient-years of active waiting time in a given year. Age is calculated on the first active listing date in a given year.



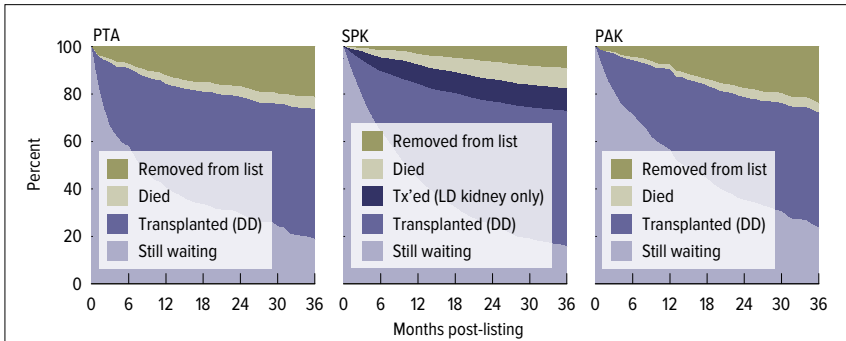
PA 1.5 Deceased donor pancreas transplant rates per 100 patient years on the waiting list among active adult candidates, by DSA, 2011–2012

Transplant rates by DSA of the listing center, limited to those with active time on the waiting list in 2011 and 2012; deceased donor transplants only. Maximum time per listing is two years. Patients with concurrent listings in a single DSA are counted once in that DSA, and those listed in multiple DSAs are counted separately per DSA.

	PTA			SPK			PAK		
	2010	2011	2012	2010	2011	2012	2010	2011	2012
Patients at start of year	497	512	471	2,169	2,184	2,092	782	688	643
Patients added during year	275	219	216	1,422	1,220	1,304	240	228	178
Patients removed during year	259	260	270	1,404	1,311	1,291	334	273	228
Patients at end of year	513	471	417	2,187	2,093	2,105	688	643	593
Removal reason									
Deceased donor transplant	149	142	121	876	834	838	157	115	89
Living donor kidney transplant	-	-	-	138	104	89	-	-	-
Patient died	25	21	12	196	150	159	25	23	16
Patient refused transplant	5	23	20	11	10	11	15	24	25
Condition improved, tx not needed	2	9	7	12	12	5	3	4	5
Too sick to transplant	15	16	10	81	79	66	34	34	28
Changed to kidney-pancreas list	12	8	7	0	0	0	15	9	12
Other	51	41	93	90	122	123	85	64	53

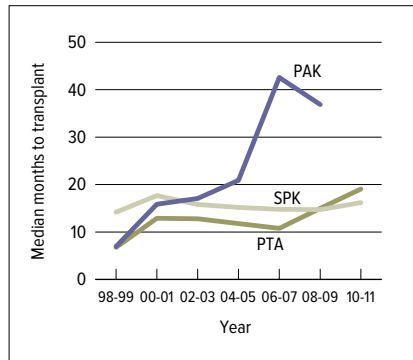
PA 1.6 Pancreas transplant waiting list activity among adult patients

Patients with concurrent listings at more than one center are counted once, from the time of earliest listing to the time of latest removal. Patients listed, transplanted, and re-listed are counted more than once. Patients are not considered “on the list” on the day they are removed. Thus, patient counts on January 1 may be different from patient counts on December 31 of the prior year. Patients listed for multi-organ transplants are included. Known deaths following removal for being too ill are counted as deaths.



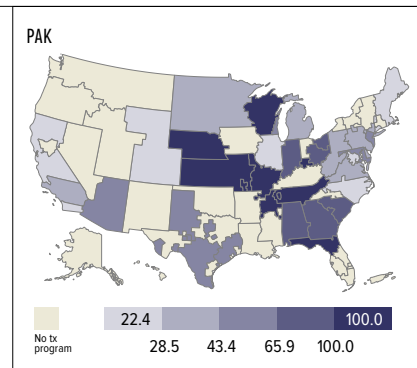
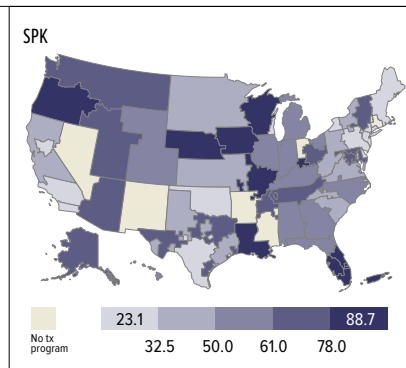
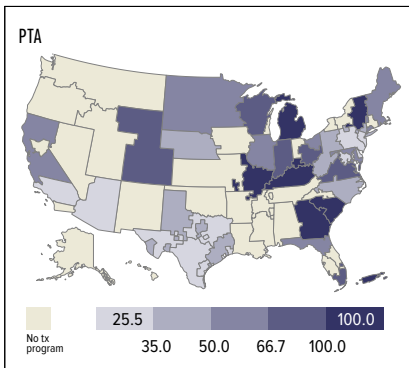
PA 1.7 Three-year outcomes for adult patients waiting for a pancreas transplant among new listings in 2009

Adult patients waiting for any pancreas transplant and first listed in 2009. Patients with concurrent listings at more than one center are counted once, from the time of the earliest listing to the time of latest removal.



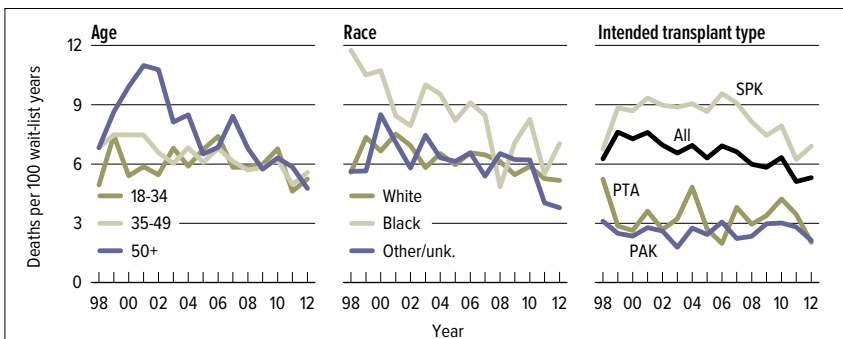
PA 1.8 Median months to pancreas tx for wait-listed adult pts

Pts waiting for a transplant, with observations censored at December 31, 2012; Kaplan-Meier methods used to estimate time to tx. If an estimate is not plotted, 50% of the cohort listed in that year had not been transplanted at the censoring date. Only the first transplant is counted.



PA 1.9 Percent of adult wait-listed patients, 2010, who received a deceased donor pancreas transplant within two years, by DSA

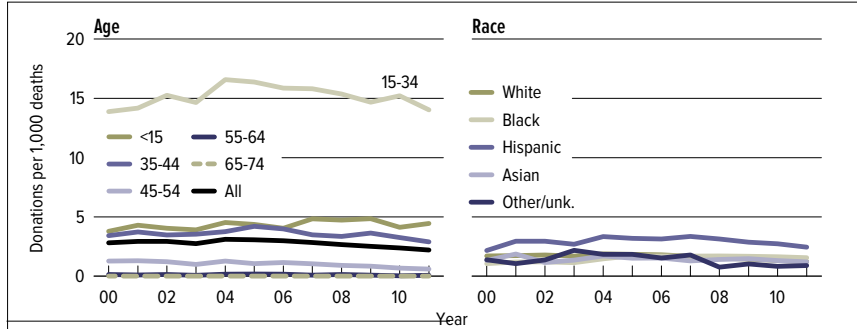
Patients with concurrent listings in a single DSA are counted once in that DSA, and those listed in multiple DSAs are counted separately per DSA.



PA 1.10 Pre-transplant mortality rates among adult patients wait-listed for a pancreas transplant

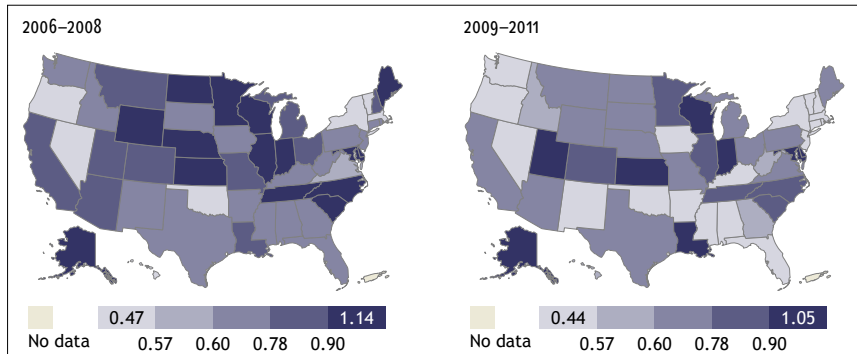
Patients waiting for a transplant. Mortality rates are computed as the number of deaths per 100 patient-years of waiting time in the given year. For rates shown by different characteristics, waiting time is calculated as the total waiting time in the year for patients in that group. Only deaths that occur prior to removal from the waiting list are counted. Age is calculated on the latest of listing date or January 1 of the given year. Other patient characteristics come from the OPTN Transplant Candidate Registration form.

donation



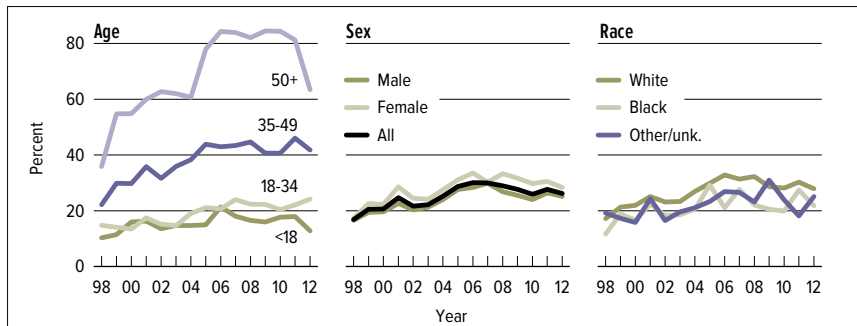
PA 2.1 Deceased donor pancreas donation rates

Numerator: Deceased donors age less than 75 with at least one pancreas recovered for transplant. Denominator: US deaths per year, age less than 75. (Death data available at <http://www.cdc.gov/nchs/products/nvsr.htm>.) Death data were available only through 2011. Pancreata recovered for islet transplantation are excluded.



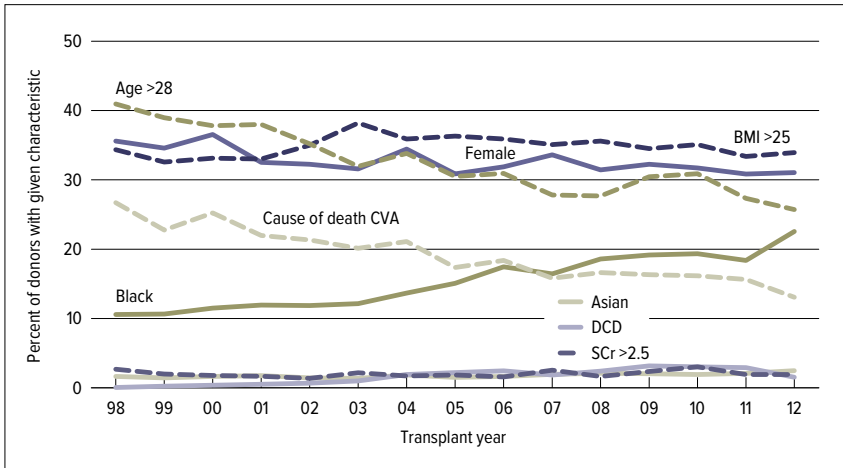
PA 2.2 Deceased donor pancreas donation rates (per 1,000 deaths), by state

Numerator: Deceased donors residing in the 50 states whose pancreas was recovered for transplant in the given year range. Denominator: US deaths by state during the given year range (death data available at <http://www.cdc.gov/nchs/products/nvsr.htm>). Rates are calculated within ranges of years for more stable estimates. Pancreata recovered for islet transplantation are excluded.

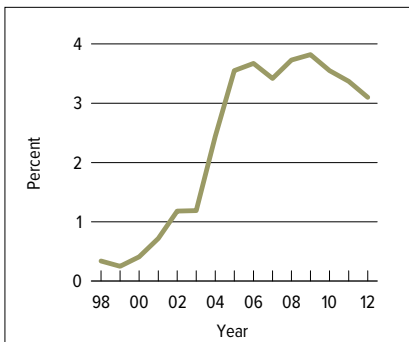


PA 2.3 Discard rates for pancreata recovered for transplant

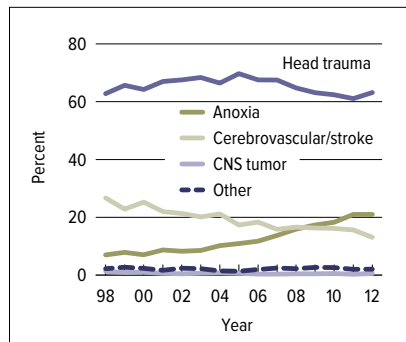
Percent of pancreata discarded out of all pancreata recovered for transplant. Pancreata recovered for islet transplantation are excluded.



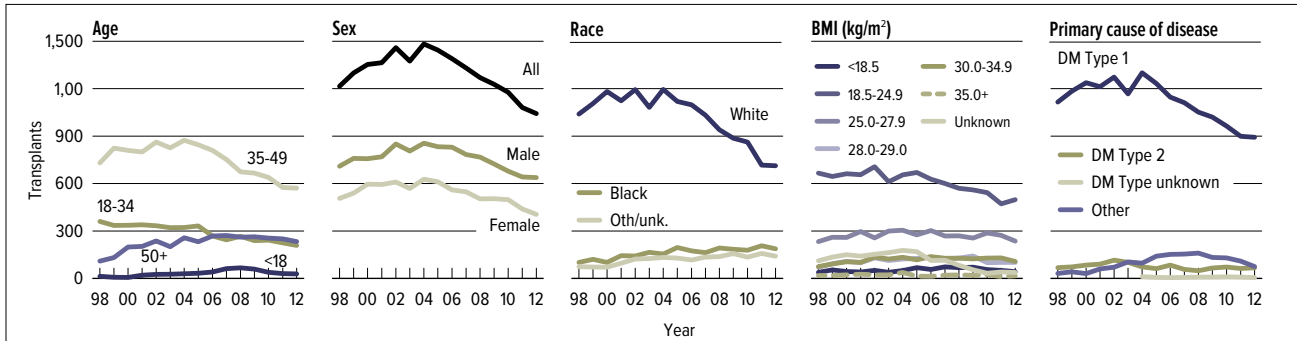
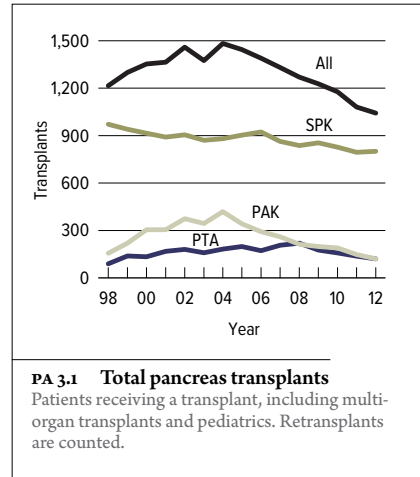
PA 2.4 Donor-specific components of pancreas donor risk (pDRI) index over time
 Donors whose pancreas was transplanted are included. The donor-specific components of the pDRI are shown.



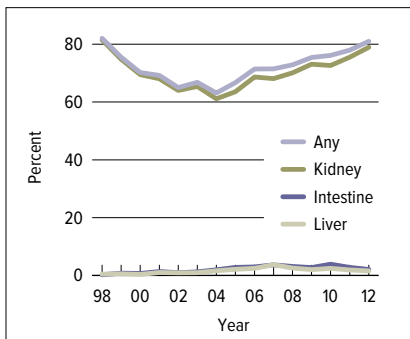
PA 2.5 Pancreas donors who are DCD
 Deceased donors whose pancreas was recovered for transplant. Pancreata recovered for islet transplantation are excluded.



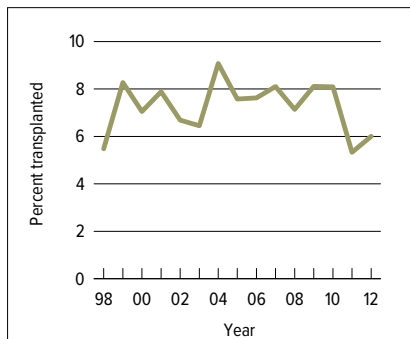
PA 2.6 Cause of death among deceased pancreas donors
 Deceased donors whose pancreas was transplanted. CNS = central nervous system.



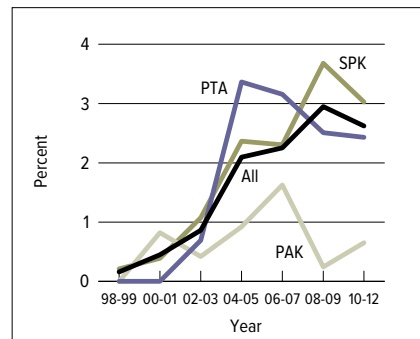
PA 3.2 Pancreas transplants
Patients receiving a transplant, including multi-organ transplants and pediatrics. Retransplants are counted.



PA 3.3 Pancreas transplants that were part of a multi-organ transplant
All adult patients receiving a deceased donor pancreas transplant with at least one additional organ. A multi-organ transplant may include more than two different organs in total; if so, each non-pancreas organ will be considered separately.

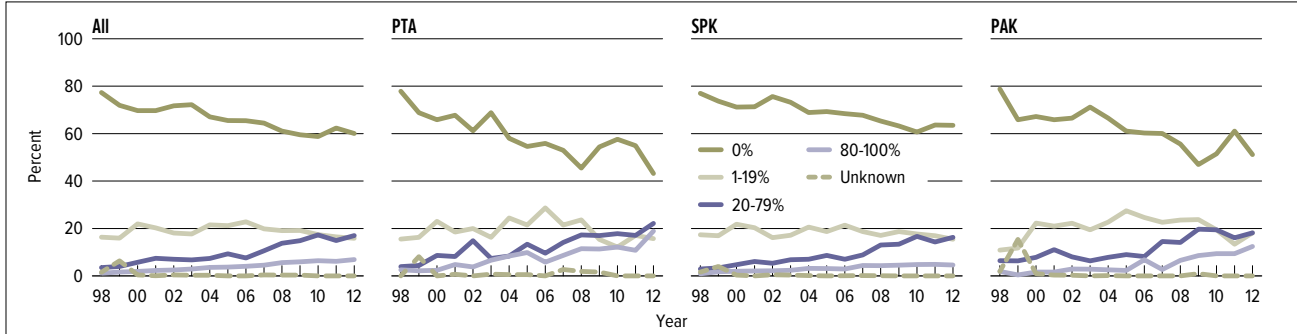


PA 3.4 Retransplants among adult pancreas transplant recipients
Patients receiving a pancreas retransplant in the given year.



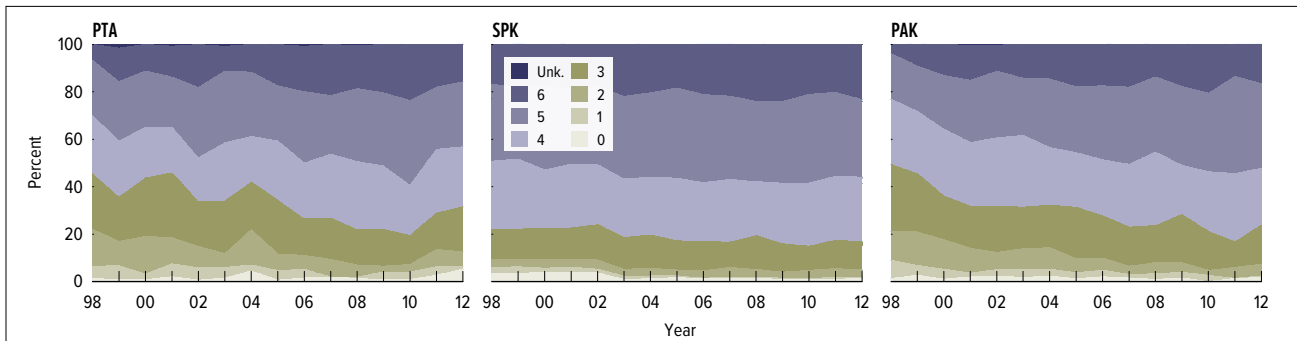
PA 3.5 Use of DCD pancreata among adult recipients, by transplant type
Percent of deceased donor transplants using a DCD donor. DCD = donation after circulatory death.

donor-recipient matching



PA 4.1 PRA at time of pancreas transplant in adult recipients

CPRA is used unconditionally from October 1, 2009 on. Between December 1, 2007 - October 1, 2009, CPRA is used if >0; otherwise, the maximum of the most recent PRA values pre-transplant is used. Prior to December 1, 2007, the maximum of the most recent PRA values pre-transplant is used unconditionally.



PA 4.2 Total HLA mismatches among adult pancreas transplant recipients

Donor and recipient antigen matching is based on the OPTN's antigen values and split equivalences policy as of 2012.

donor-recipient matching

RECIPIENT	DONOR			Total
	Negative	Positive	Unknown	
Negative	19.6	26.9	0.2	46.7
Positive	19.9	30.8	0.1	50.8
Unknown	0.9	1.6	0.0	2.5
Total	40.4	59.3	0.3	100

PA 4.3 Adult pancreas donor-recipient cytomegalovirus (CMV) serology matching, 2008–2012

Adult transplant cohort from 2008–2012. Donor serology is reported on the OPTN donor registration forms; recipient serology is reported on the OPTN recipient registration forms. Any evidence for a positive serology is taken to indicate that the person is positive for the given serology; if all fields are unknown, not done, or pending, the person is considered to be “unknown” for that serology; otherwise, serology is assumed negative.

RECIPIENT	DONOR			Total
	Negative	Positive	Unknown	
Negative	1.5	13.4	0.3	15.1
Positive	5.4	64.6	0.6	70.6
Unknown	0.8	13.2	0.2	14.2
Total	7.8	91.2	1.0	100

PA 4.4 Adult pancreas donor-recipient Epstein-Barr virus (EBV) serology matching, 2008–2012

Adult transplant cohort from 2008–2012. Donor serology is reported on the OPTN donor registration forms; recipient serology is reported on the OPTN recipient registration forms. Any evidence for a positive serology is taken to indicate that the person is positive for the given serology; if all fields are unknown, not done, or pending, the person is considered to be “unknown” for that serology; otherwise, serology is assumed negative.

RECIPIENT	DONOR			Total
	Negative	Positive	Unknown	
Negative	79.9	0.5	0.1	80.5
Positive	3.3	0.1	0.0	3.3
Unknown	16.1	0.1	0.0	16.2
Total	99.2	0.7	0.1	100

PA 4.5 Adult pancreas donor-recipient hepatitis B core antibody (HBCAb) serology matching, 2008–2012

Adult transplant cohort from 2008–2012. Donor serology is reported on the OPTN donor registration forms; recipient serology is reported on the OPTN recipient registration forms. Any evidence for a positive serology is taken to indicate that the person is positive for the given serology; if all fields are unknown, not done, or pending, the person is considered to be “unknown” for that serology; otherwise, serology is assumed negative.

RECIPIENT	DONOR			Total
	Negative	Positive	Unknown	
Negative	94.4	0.0	0.1	94.5
Positive	1.2	0.0	0.0	1.2
Unknown	4.3	0.0	0.0	4.3
Total	99.9	0.0	0.1	100

PA 4.6 Adult pancreas donor-recipient hepatitis B surface antigen (HBsAg) serology matching, 2008–2012

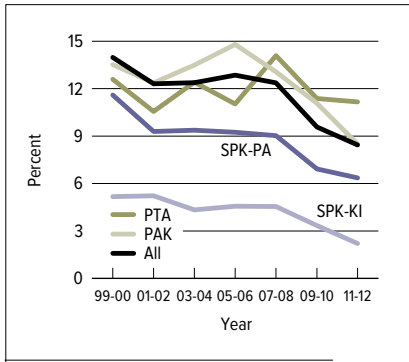
Adult transplant cohort from 2008–2012. Donor serology is reported on the OPTN donor registration forms; recipient serology is reported on the OPTN recipient registration forms. Any evidence for a positive serology is taken to indicate that the person is positive for the given serology; if all fields are unknown, not done, or pending, the person is considered to be “unknown” for that serology; otherwise, serology is assumed negative.

RECIPIENT	DONOR			Total
	Negative	Positive	Unknown	
Negative	93.1	0.0	0.1	93.1
Positive	2.1	0.0	0.0	2.2
Unknown	4.7	0.0	0.0	4.7
Total	99.9	0.0	0.1	100

PA 4.7 Adult pancreas donor-recipient hepatitis C serology matching, 2008–2012

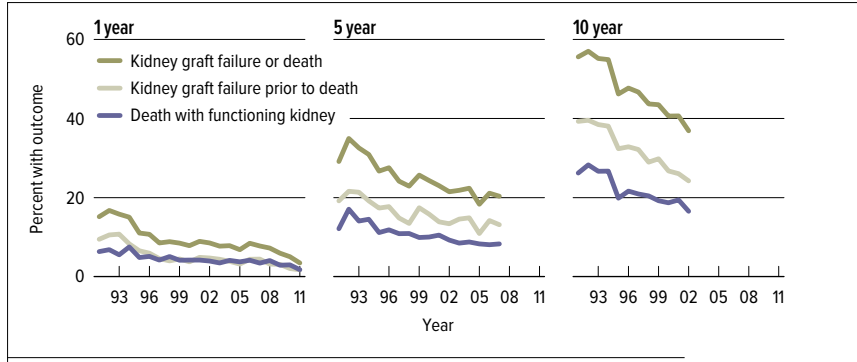
Adult transplant cohort from 2008–2012. Donor serology is reported on the OPTN donor registration forms; recipient serology is reported on the OPTN recipient registration forms. Any evidence for a positive serology is taken to indicate that the person is positive for the given serology; if all fields are unknown, not done, or pending, the person is considered to be “unknown” for that serology; otherwise, serology is assumed negative.

outcomes



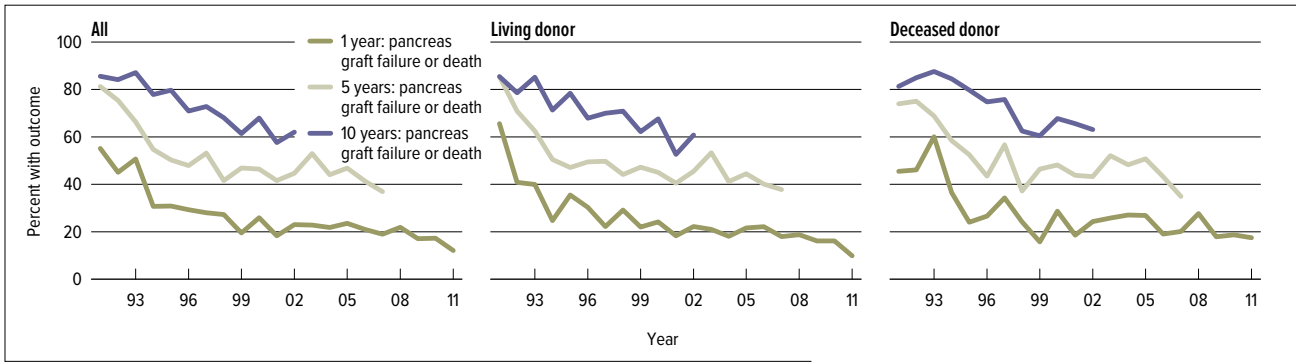
PA 5.1 Graft failure within the first 90 days after transplant among adult pancreas transplant recipients

All-cause graft failure is identified from multiple data sources, including the OPTN Transplant Recipient Registration form and OPTN Transplant Recipient Follow-up form, as well as death dates from the Social Security Administration. Transplants through September 30, 2012 are included to allow for sufficient follow-up.



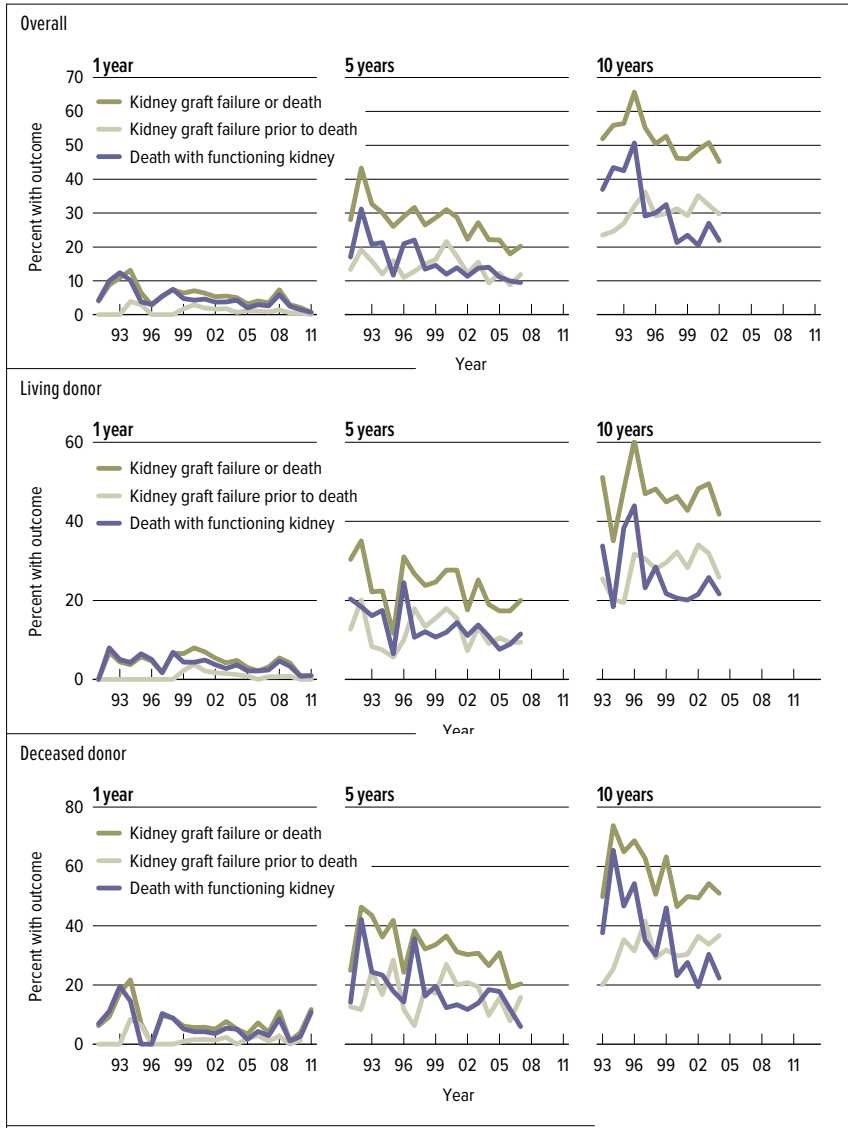
PA 5.2 Outcomes among adult SPK transplant recipients: kidney outcomes

Cox proportional hazards models, adjusted for age, sex, and race. Simultaneous kidney-pancreas (SPK) transplant recipients are followed from date of transplant until the first of kidney graft failure, kidney retransplant, return to dialysis, death, or loss-to-follow-up.



PA 5.3 Pancreas graft failure among adult PAK transplant recipients, by kidney donor type

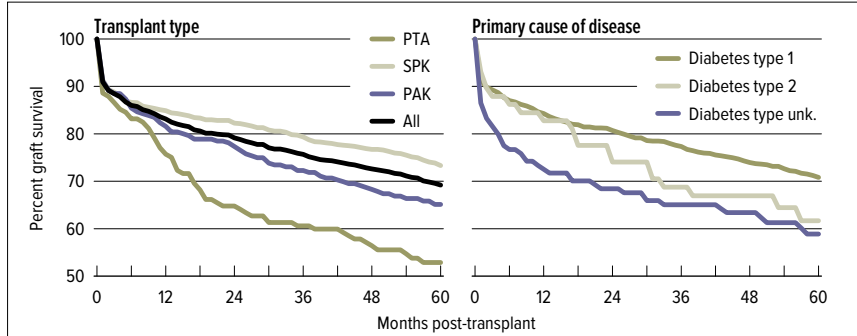
Cox proportional hazards models, adjusted for age, sex, and race. Pancreas-after-kidney (PAK) transplant recipients are followed from date of transplant until the first of pancreas graft failure, pancreas retransplant, death, or loss-to-follow-up. Only PAK recipients with a record of a previous KI/KP transplant are included.



PA 5.4 Outcomes among adult PAK transplant recipients: kidney outcomes (from time of pancreas transplant)

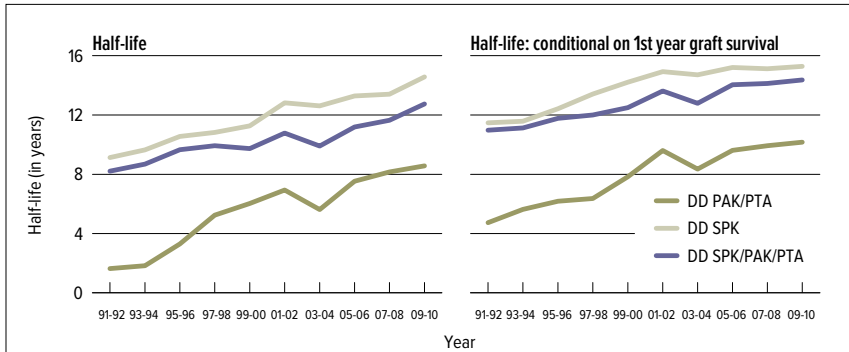
Cox proportional hazards models, adjusted for age, sex, and race. Pancreas-after-kidney (PAK) transplant recipients are followed from date of pancreas transplant until the first of kidney graft failure, kidney retransplant, return to dialysis, death, or loss-to-follow-up. Only PAK recipients with a record of a previous KI/KP transplant are included.

outcomes



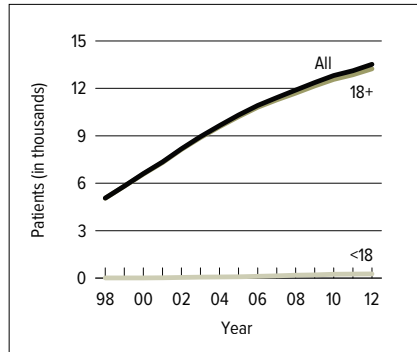
PA 5.5 Graft survival among adult pancreas transplant recipients transplanted in 2007: deceased donors

Pancreas graft survival estimated using unadjusted Kaplan-Meier methods.



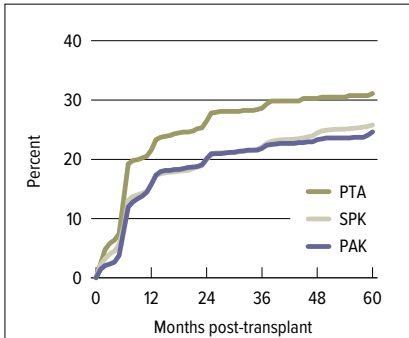
PA 5.6 Half-lives for adult pancreas transplant recipients

The half-life for a transplant cohort (e.g. 2009 pancreas transplants) is the time point in follow-up at which 50% of the transplanted grafts have failed. A conditional half life for a transplant cohort is the same calculation but limited to those who survive with function at least 1 year post-transplant.



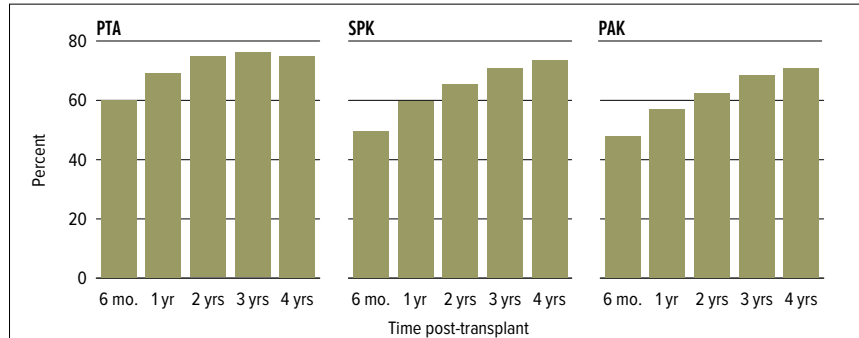
PA 5.7 Recipients alive & with a functioning pancreas transplant on June 30 of the year

Transplants before June 30 of the year that are still functioning. Patients are assumed alive with function unless a death or graft failure is recorded. A recipient can experience a graft failure and drop from the cohort, then be retransplanted and re-enter the cohort. Age cut is based on age at transplant.



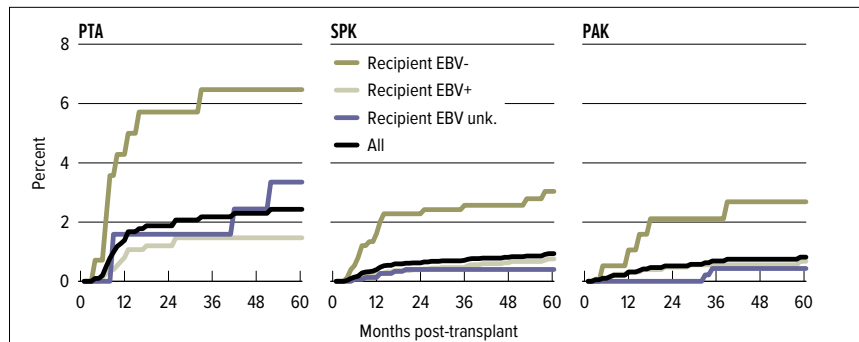
PA 5.8 Incidence of first acute rejection among adult patients receiving a pancreas transplant in 2006–2010

Acute rejection defined as a record of acute or hyperacute rejection, or a record of an anti-rejection drug being administered on either the Transplant Recipient Registration form or the Transplant Recipient Follow-up form. Only the first rejection event is counted. Cumulative incidence, defined as the probability of acute rejection at any time prior to the given time, is estimated using Kaplan-Meier competing risk methods.



PA 5.9 Reported cumulative incidence of rehospitalizations among adult patients receiving a pancreas transplant in 2007–2012

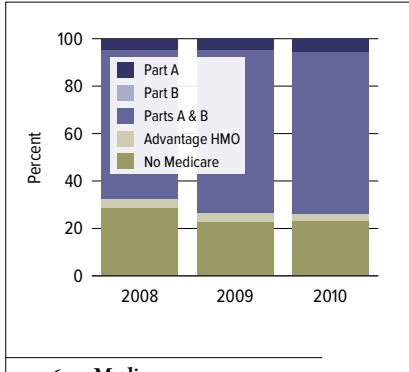
Cumulative rate of rehospitalization; hospitalization identified from follow-up form. Patients required to be alive with graft function at each time period, so denominators reduce over time.



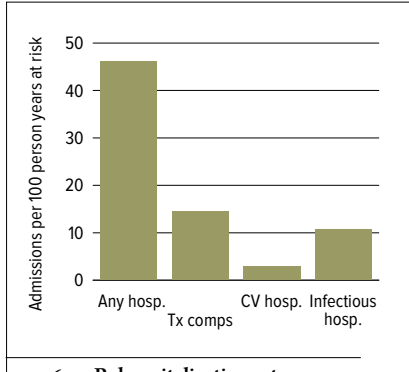
PA 5.10 Incidence of PTLD among adult patients receiving a pancreas transplant in 2006–2010, by recipient Epstein-Barr virus (EBV) status at transplant

The cumulative incidence is estimated using Kaplan-Meier competing risks methods. PTLD is identified as either a reported complication or cause of death on the Transplant Recipient Follow-up forms or on the Post-transplant Malignancy form as polymorphic PTLD, monomorphic PTLD, or Hodgkin's Disease. Only the earliest date of PTLD diagnosis is considered.

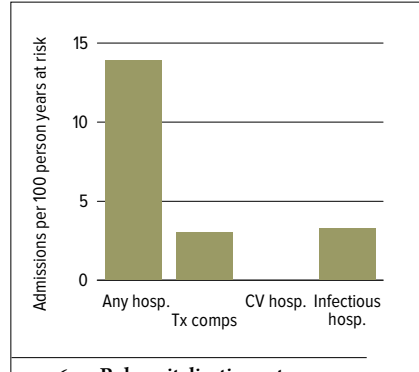
Medicare data



PA 6.1 Medicare coverage among pancreas transplant recipients
Coverage at the time of transplant as identified by the Medicare Beneficiary Annual Summary supplied by CMS.



PA 6.2 Rehospitization rates among pancreas transplant recipients in the first post-transplant year
Transplant recipients, 2008, with Medicare as the primary payer at transplant. Rehospitizations and reasons for rehospitization determined from Medicare claims. First year rates are based on rehospitizations occurring from initial discharge to one year later.



PA 6.3 Rehospitization rates among pancreas transplant recipients in the second post-transplant year
Transplant recipients, 2008, with Medicare as the primary payer at transplant. Rehospitizations and reasons for rehospitization determined from Medicare claims. Second year rates are based on hospitalizations occurring from initial discharge+1 year to initial discharge+2 years.

Year 1 Cause of hospitalization	Percent of hospitalizations	Year 2 Cause of hospitalization	Percent of hospitalizations
Transplant complication	27.9	Transplant complication	21.0
Other infection	13.5	Gastro-intestinal	14.6
Other	10.5	Metabolic, endocrine, nutritional	13.9
Gastro-intestinal	9.9	Other infection	10.0
Electrolyte, acid-base & volume depletion	8.5	Other	7.7
Metabolic, endocrine, nutritional	6.8	Bacteremia, viremia & septicemia	5.2
Urinary tract infection	4.3	Urinary tract infection	5.2
Bacteremia, viremia and septicemia	3.2	Electrolyte, acid-base & volume depletion	4.8
Immune and hematologic	2.7	Respiratory infection	2.7
Genito-urinary and breast	2.7	Genito-urinary and breast	2.5

PA 6.4 Top ten causes of rehospitization among pancreas recipients transplanted in 2008 with Medicare primary coverage
Transplant recipients, 2008, with Medicare as the primary payer at transplant. Reasons for rehospitization determined from Medicare claims, denominator for percentages includes only those re-hospitalized.

		# patients	Total costs		PPPY costs	
			Part A	Part B	Part A	Part B
All patients		1,046	91,133,188	23,294,904	98,440	25,163
Age	18-34	248	20,467,804	5,798,001	92,287	26,143
	35-49	595	50,147,424	13,123,747	96,984	25,381
	50-64	199	20,091,681	4,292,203	109,843	23,466
	65+	*	*	*	*	*
Sex	Male	672	55,751,965	14,811,920	93,554	24,855
	Female	374	35,381,223	8,482,985	107,266	25,718
Race	White	694	60,130,774	14,607,848	98,006	23,809
	Black	204	18,132,630	4,972,532	100,433	27,542
	Hispanic	126	10,269,645	3,184,558	90,262	27,990
	Asian/Pac. Isl.	16	1,712,267	378,756	134,000	29,641
	Other/unk.	*	*	*	*	*
Primary cause of disease	Diabetes Type 1	892	75,605,427	19,409,839	96,109	24,674
	Diabetes Type 2	70	6,621,616	1,796,795	102,855	27,910
	DM Type unk.	13	981,059	293,273	75,260	22,498
	Other/unk.	71	7,925,086	1,794,997	128,437	29,090

PA 6.5 Total and per-person per-year (PPPY) Medicare costs (\$) among pancreas transplant recipients in the first post-transplant year

Costs among recipients transplanted in 2008 and 2009 who had Medicare as the primary payer at the time of transplant. First year costs include the transplant hospitalization. Costs incurred after a transplant failure are excluded. Values for cells with 9 or fewer patients are suppressed.

		# patients	Total costs		PPPY costs	
			Part A	Part B	Part A	Part B
All patients		400	6,604,595	5,621,757	16,842	14,335
Age	18-34	104	2,095,932	1,519,943	20,638	14,966
	35-49	220	3,367,219	3,203,231	15,462	14,709
	50-64	74	1,057,612	880,522	14,933	12,432
	65+	*	*	*	*	*
Sex	Male	260	3,782,130	3,612,619	14,802	14,139
	Female	140	2,822,465	2,009,138	20,655	14,703
Race	White	261	4,350,602	3,393,734	17,113	13,349
	Black	83	1,812,105	1,451,117	22,027	17,639
	Hispanic	50	406,916	708,644	8,195	14,272
	Asian/Pac. Isl.	*	*	*	*	*
	Other/unk.	*	*	*	*	*
Primary cause of disease	Diabetes Type 1	339	5,434,798	4,683,190	16,384	14,118
	Diabetes Type 2	26	311,761	441,104	12,185	17,240
	DM Type unk.	*	*	*	*	*
	Other/unk.	27	766,658	395,083	28,566	14,721

PA 6.6 Total and per-person per-year (PPPY) Medicare costs (\$) among pancreas transplant recipients in the second post-transplant year

Costs among recipients transplanted in 2008 who had Medicare as the primary payer at the time of transplant. The second post-transplant year runs from 366 to 730 days after transplant. Costs incurred after a transplant failure are excluded. Values for cells with 9 or fewer patients are suppressed.

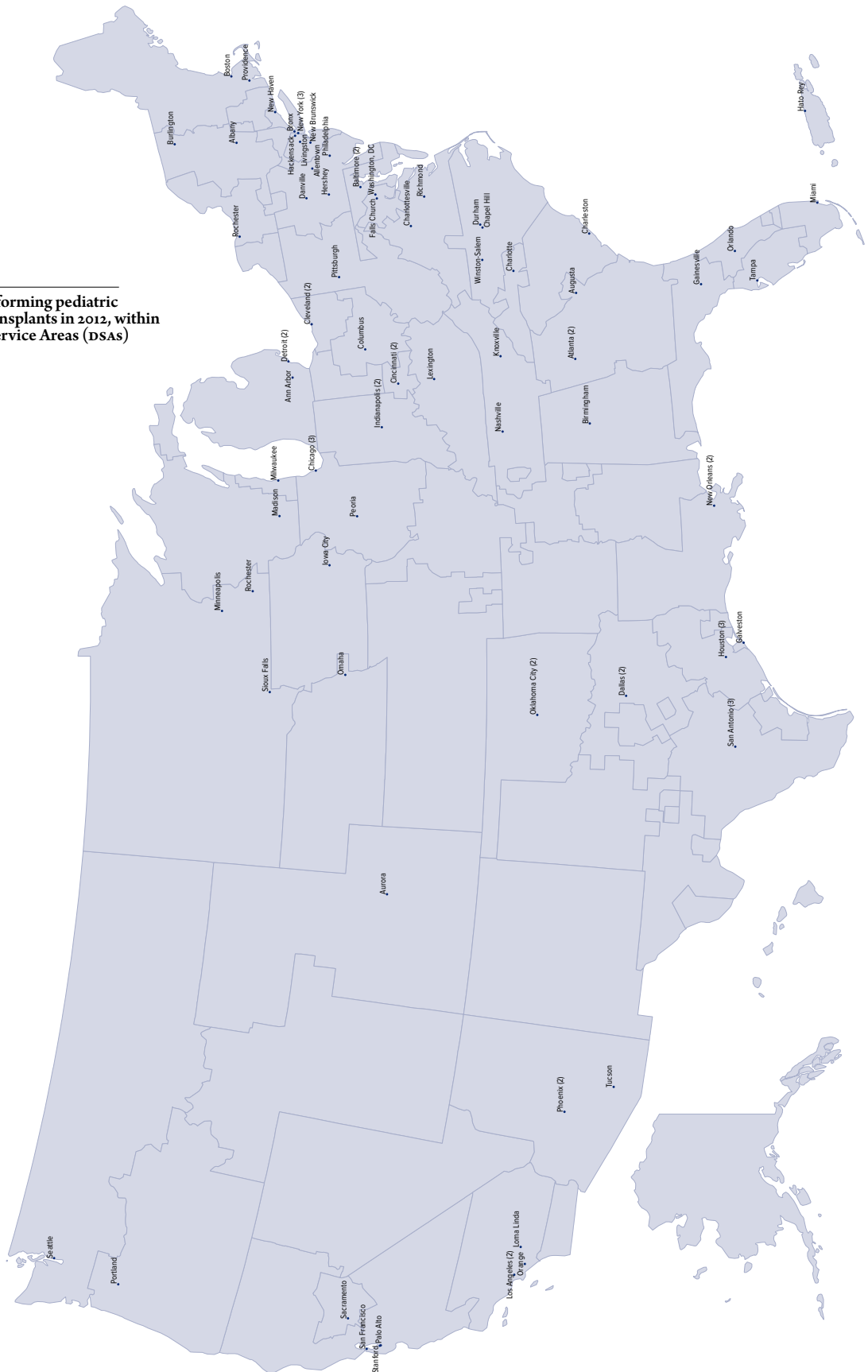
Medicare data

Total costs		2008 total costs			2009 total costs			2010 total costs		
		# patients	Part A	Part B	# patients	Part A	Part B	# patients	Part A	Part B
All patients		7,359	134,601,264	55,370,281	7,633	149,704,141	70,629,865	7,808	155,230,859	68,709,534
Age	0-11	*	*	*	*	*	*	*	*	*
	12-17	*	*	*	*	*	*	*	*	*
	18-34	1,894	39,726,811	15,682,532	1,915	41,720,581	19,549,606	1,958	43,789,217	18,977,488
	35-49	4,330	71,069,443	31,336,181	4,463	40,264,491	40,264,491	4,528	83,098,598	38,674,969
	50-64	1,112	22,894,521	8,109,516	1,231	24,636,875	10,583,869	1,296	27,580,809	10,770,066
	65+	16	562,925	134,093	18	333,047	172,021	18	532,279	205,903
Sex	Male	4,445	79,251,852	33,485,360	4,609	86,655,657	42,808,135	4,702	88,801,380	40,626,491
	Female	2,914	55,349,412	21,884,921	3,024	63,048,484	27,821,730	3,106	66,429,480	28,083,044
Race	White	5,858	101,594,685	41,301,659	6,023	111,186,012	52,144,335	6,091	113,770,061	50,170,199
	Black	880	20,832,491	8,509,128	941	23,157,671	11,009,386	1,013	25,590,098	11,341,381
	Hispanic	517	10,077,090	4,693,295	554	12,693,185	6,353,311	584	12,287,303	6,074,537
	Asian/Pacific Islander	70	1,438,481	637,644	76	1,873,581	813,331	77	1,937,796	701,154
	Other/unk.	34	658,516	228,555	39	793,692	309,502	43	1,645,602	422,263
Primary cause of disease	Diabetes Type 1	5,979	105,759,707	44,371,166	6,215	118,912,396	57,307,999	6,379	120,385,010	55,319,580
	Diabetes Type 2	436	8,570,790	3,647,292	468	9,674,931	4,715,828	483	11,293,695	4,801,071
	Diabetes Type unk.	28	845,375	249,991	35	810,904	348,733	38	648,457	375,009
	Other/unk.	916	19,425,392	7,101,832	915	20,305,910	8,257,304	908	22,903,697	8,213,874
Per person per year costs		2008 PPPY costs			2009 PPPY costs			2010 PPPY costs		
		# patients	Part A	Part B	# patients	Part A	Part B	# patients	Part A	Part B
All patients		7,359	20,004	8,229	7,633	21,474	10,131	7,808	21,673	9,593
Age	0-11	*	*	*	*	*	*	*	*	*
	12-17	*	*	*	*	*	*	*	*	*
	18-34	1,894	22,756	8,983	1,915	23,579	11,049	1,958	24,365	10,559
	35-49	4,330	17,929	7,905	4,463	20,228	9,840	4,528	19,953	9,287
	50-64	1,112	22,953	8,130	1,231	22,613	9,714	1,296	23,424	9,147
	65+	16	37,618	8,961	18	22,512	11,627	18	35,382	13,687
Sex	Male	4,445	19,591	8,277	4,609	20,630	10,191	4,702	20,645	9,445
	Female	2,914	20,628	8,156	3,024	22,754	10,041	3,106	23,219	9,816
Race	White	5,858	18,878	7,675	6,023	20,090	9,422	6,091	20,240	8,925
	Black	880	26,504	10,826	941	27,667	13,153	1,013	28,332	12,557
	Hispanic	517	21,610	10,065	554	25,378	12,703	584	23,249	11,494
	Asian/Pacific Islander	70	22,870	10,138	76	28,606	12,418	77	26,830	9,708
	Other/unk.	34	20,728	7,194	39	23,183	9,040	43	44,123	11,322
Primary cause of disease	Diabetes Type 1	5,979	19,399	8,139	6,215	20,962	10,102	6,379	20,576	9,455
	Diabetes Type 2	436	21,190	9,017	468	22,839	11,133	483	25,799	10,968
	Diabetes Type unk.	28	34,862	10,309	35	26,650	11,461	38	19,106	11,049
	Other/unk.	916	22,908	8,375	915	24,042	9,777	908	27,273	9,781

PA 6.7 Total calendar-year Medicare costs (\$) spent on pancreas transplant recipients, 2008, 2009, & 2010

Costs paid by Medicare in each calendar year among recipients alive with graft function in the given year, regardless of Medicare eligibility at the time of transplant. Costs incurred after transplant failure are excluded. Values for cells with 9 or fewer patients are suppressed.

PA 7.2 Centers performing pediatric pancreas transplants in 2012, within Donation Service Areas (DSAs)



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OPTN/SRTR 2012 Annual Data Report:

liver

ABSTRACT Liver transplant in the US remains a successful life-saving procedure for patients with irreversible liver disease. In 2012, 6256 adult liver transplants were performed, and more than 65,000 people were living with a transplanted liver. The number of adults who registered on the liver transplant waiting list decreased for the first time since 2002; 10,143 candidates were added, compared with 10,359 in 2011. However, the median waiting time for active wait-listed adult candidates increased, as did the number of candidates removed from the list because they were too sick to undergo transplant. The overall deceased donor transplant rate decreased to 42.3 per 100 patient-years, and varied geographically from 18.9 to 228.0 per 100 patient-years. Graft survival continues to improve, especially for donation after circulatory death livers. The number of new active pediatric candidates added to the waiting list also decreased. Almost 75% of pediatric candidates listed in 2009 underwent transplant within 3 years; the 2012 rate of deceased donor transplants among active pediatric wait-listed candidates was 136 per 100 patient-years. Graft survival for deceased donor pediatric transplants was 92.8% at 30 days. Medicare paid for some or all of the care for more than 30% of liver transplants in 2010.

KEY WORDS Liver transplant, model for end-stage liver disease, waiting list.

When I awoke from surgery three and a half days later, while still on life support I spoke my first words, "She was younger than I." My surgeon teared up, "And she has three children!" I have had normal liver functions for the past seven years thanks to my 44-year old donor.

Ronald, liver recipient

Adult Liver Transplant

INTRODUCTION

In 2012, 6256 liver transplants were performed in the United States (Figure 4.1). These included transplant of 5747 organs from donation after brain death (DBD) donors, 263 from donation after circulatory death (DCD) donors, and 246 from living donors. Organs were procured from across the country and transplanted at 132 transplant centers. For deceased donor recipients who underwent transplant in 2007, these life-saving operations yielded an unadjusted 5-year survival of 70.5% (Figure 6.4). Based on Medicare data, incorporated into the Annual Data Report for the first time this year, liver transplants cost an average of \$188,000 during the first year after transplant. More importantly, human costs were substantial; in 2012, 2187 patients died while on the waiting list, and 815 were removed from the list because they were too sick to undergo transplant (Figure 1.6). Ultimately, liver transplant in the US remains a successful life-saving procedure for patients with irreversible liver disease. As of June 30, 2012, more than 65,000 people were living with a liver transplant; 57,000 had undergone transplant as adults and 8700 as children (Figure 6.7).

WAITING LIST

During 2012, 10,143 candidates were added to the liver transplant waiting list (Figure 1.6), most with active status ($n = 9708$, 96%; Figure 1.1). This compares with 10,359 candidates added in 2011 and represents a decrease of 216 (2.1%), the first decrease in wait-list registrations since 2002. Similarly, the number of active wait-list candidates on December 31, 2012, was 12,427, compared with 12,635 one year before. Whether such decreases will continue remains to be seen, but if future data confirm a decreasing demand for liver transplant, it will represent a reversal of a trend that has persisted since liver transplant became recognized as an established procedure. A possible explanation of the decreases may be positive, such as successful treatment of viral hepatitis or better management of patients with advanced liver disease. Conversely, the explanation may be negative, such as aging patients with hepatitis C virus (HCV) infection being rejected from transplant candidacy, or increasing comorbidity in patients with end-stage liver disease or hepatocellular carcinoma (HCC)

related to increasing prevalence of obesity and related metabolic and cardiovascular complications.

Figure 1.2 shows further trends among liver transplant wait-list candidates. The proportion of older patients (aged 65 years or older) increased. Model for end-stage liver disease (MELD) scores at registration were most commonly between 6 (the lower bound) and 14, but the proportion of scores between 15 and 34 is growing steadily. The distribution of liver disease etiology remains unchanged, except for malignancy. This trend is a part of larger phenomena of increasing incidence of HCC and rapidly increasing numbers of liver transplant candidates and recipients with HCC exceptions (also see Figure 1.3). Figure 1.4 shows a similar trend with regard to HCC; deceased donor transplant rates among active adult candidates with HCC exceptions were nearly three times higher than rates among those without HCC exceptions. The overall transplant rate has been gradually declining since 2006; greater decline was seen in candidates with HCC exceptions and in candidates aged 18 to 34 years.

The decrease in transplant rates reflects the gradually worsening donor shortage. Despite the decline in wait-list registration, the median pretransplant waiting time among active wait-listed adult patients increased from 12.9 months in 2009 to 17.6 months in 2010 and to 18.5 months in 2011 (Figure 1.8). Pretransplant mortality rates decreased in 2012, for the first time in several years (Figure 1.10).

Among active adult wait-list candidates, the overall deceased donor transplant rate was 42 per 100 patient-years on the waiting list (Figure 1.4). However, geographic variability in transplant rates was considerable. Within the continental US, rates ranged from 18.9 per 100 patient-years on the waiting list to 228.0, more than a 10-fold difference (Figure 1.5). Median MELD scores at the time of transplant also varied widely by donation service area (DSA). Within the continental US, median MELD scores were 22 in several DSAs, and the highest MELD scores were in DSAs located in California and New York (Figure 4.9).

Similarly, the proportion of adults receiving deceased donor organs within 5 years of listing ranged from 30.5% in a DSA in New York to 86.1% in the Arkansas DSA (Figure 1.9). These differences are striking, and the solution to geographic disparity remains a challenge. There is an inverse correlation

between transplant rates and median MELD scores by DSA. Increasing donation represents the most ideal solution for the donor shortage; there is no clear correlation between the organ donation rate and the median MELD score at transplant (Figure 2.2).

DONATION

Figure 2.1 shows the trend in organ donation rates over time. Rates peaked in 2006 and have been decreasing since, despite modest increases from donors aged 15 to 34 and 35 to 44 years. Figure 2.5 shows that the proportion of donors who died of cerebral anoxia has been increasing. The proportion of DCD donors has been stable since 2005 (Figure 2.4).

The total number of living donor liver transplants has been stable since 2008 (Figure 3.1). However, right lobe donation increased slightly from 57.8% of total living donors in 2010 to 63.7% in 2012 (Figure 3.3). The most noticeable recent trend in living donor transplant is data that suggest worsening short-term outcomes for donors. The number of donors with biliary complications reported to OPTN more than doubled, from 6 cases (2.5%) in 2011 to 14 (6.4%) in 2012 (Figure 3.5). The number of vascular complications also increased, from just 1 case in 2010 and 2011 to 7 in 2012 (Figure 3.6). Complications other than biliary and vascular increased modestly (Figure 3.7). Donor rehospitalization within 6 weeks of organ donation increased from 7.8% to 9.7% between 2010 and 2011, and rehospitalization within 6 months increased from 8.6% to 11.4% (Figure 3.4). Conversely, the number of donors who required reoperation decreased and, most importantly, no donor deaths were reported in 2012.

TRANSPLANT

Data on recipients show a continued trend toward older ages. The number of recipients aged 65 years or older more than doubled, from 363 in 2002 to 835 in 2012 (Figure 4.2). The largest group of recipients, those aged 50 to 64 years, increased from 2433 in 2002 to 3623 in 2012. However, the most noticeable trend in recipient characteristics is the rapidly rising number and proportion of recipients with a primary diagnosis of malignancy; the number increased from 432 in 2002 to 1337 in 2012 (Figure 4.2). The most common diagnosis in recipients remains HCV, which likely contributes to the number of recipients with

malignancy as the primary diagnosis at transplant (Figure 4.2). In keeping with the trend in the general population toward increasing prevalence of obesity, the proportion of recipients with body mass index (BMI) 30 kg/m² or higher increased from 29.0% in 2002 to 35.4% in 2012 (Figure 4.7). Because many liver transplant candidates have ascites and fluid retention, high BMI does not necessarily indicate obesity. However, increasing prevalence of diabetes during the same time period (18.2% to 24.6%) suggests increasing obesity (Figure 4.7).

Nationwide, the median match MELD score for transplant in 2012 was 27 (Figure 4.9). However, geographic disparity in median MELD scores remains wide. In DSAs in the continental US, the lowest median MELD score was 21 and the highest 35. In eight DSAs, median MELD scores were 30 or higher in 2012. A substantial part of this variation is due to differences in lab MELD and match MELD scores by DSA. Score adjustments are common for HCC, and nationwide the median difference between lab and match MELD scores is 2 points, but it varies from 0 to 11 points (Figure 4.10). In DSAs with the highest median match MELD scores, the median difference between lab and match MELD scores was also largest. There is a consensus that the adjustment score for patients with HCC may still be too high, disadvantaging patients with severe end-stage liver disease without HCC. Work attempting to address the gap is underway.

The proportion of multi-organ transplants is increasing, a trend led by simultaneous liver and kidney (SLK) transplants. In 2012, 8.4% of all deceased donor transplants were multi-organ; of these, 92% were SLK transplants (Figure 4.3). The issue of increasing use of SLK transplants has been a topic of many discussions, debates, and publications. The trend is due to several factors, the most important of which is the worsening condition of liver transplant candidates with end-stage liver disease, leading to higher incidence of hepatorenal syndrome and other renal complications. Of note, the current allocation system, which takes into account renal function of liver candidates, may not be the only cause of the increase in SLK. Indeed, it is possible that, given the continued organ shortage and increasing severity of end-stage liver disease, patients with adequate renal function may be left with their liver disease progressing, potentially resulting in an even greater need for SLK transplant.

Tacrolimus-based immunosuppression after transplant was reported for most patients (Figure 4.8). Reported use of mycophenolate and to a lesser extent azathioprine increased, and reported use of steroids decreased (Figure 4.8). Use of mammalian target of rapamycin (mTOR) inhibitors at transplant was reported in approximately 3% of recipients, and within the first year after transplant in 9%. The proportion of liver recipients reported to be undergoing induction therapy, particularly with an interleukin-2 receptor antagonist, has been increasing (Figure 4.8). Some of these trends may be related to the small but significant proportion of patients undergoing SLK transplant.

OUTCOMES

Continued improvement in overall graft survival is encouraging (Figures 6.2 and 6.6). Figure 6.1 shows that 90-day graft survival for all deceased donor livers consistently improved in the past decade. Of note, DCD graft survival substantially improved over time. Living donor graft survival abruptly worsened, reversing the previous trend of consistent improvement (Figure 6.1). This, combined with less favorable donor outcomes discussed previously, may raise concerns about the practice of living donor liver transplant as a whole and may deserve closer scrutiny. Figure 6.5 shows the analysis of living donor transplant outcomes by subgroup.

In subgroup analyses, outcomes were poorest for older patients, patients with the highest MELD scores, and patients with HCV (Figure 6.4). DCD grafts survived less well than DBD grafts; the gap developed during the first year after transplant and continued over time. Survival of retransplant grafts was lower than survival of primary grafts, which is also well documented.

As of June 30, 2012, 56,900 adult liver transplant recipients were alive, a number that testifies to the success of the nationwide practice of liver transplant. This total number of liver recipients alive in 2012 was almost exactly twice the number alive 10 years before (28,500 in 2002).

Pediatric Transplant

WAITING LIST

The number of new active candidates added to the pediatric liver transplant waiting list has steadily decreased, and very

few have been added as inactive (Figure 7.1). A similar trend is the decreasing numbers of prevalent wait-listed patients (those on the list on December 31 of the given year), of whom most (60%) are listed as active. The age distribution of wait-listed candidates changed little over the past decade. In 2012, 22.5% of candidates were aged less than 1 year, 26.9% were aged 1 to 5 years, 15.3% were aged 6 to 10 years, and 35.4% were aged 11 to 17 years (Figure 7.2). Half of the wait-list candidates have been waiting for less than 1 year, 19.6% for 1 to less than 2 years, 11.7% for 2 to less than 4 years, and 18.9% for 4 or more years. In 2012, 13.1% of wait-list candidates ($n = 85$) had undergone a previous liver transplant (Figure 7.3). Of all wait-list candidates in 2012, 10.3% (43) of those aged less than 6 years, 20.5% (16) of those aged 6 to 10 years, and 17.0% (26) of those aged 11 to 17 years were waiting for retransplant (Figure 7.3). Among candidates removed from the waiting list in 2012, 66.0% received a deceased donor liver, 7.5% received a living donor liver, 5.2% died, 13.7% were removed from the list because their condition improved, and 2.4% were considered too sick to undergo transplant (Figure 7.4). Almost 75% of patients newly listed in 2009 underwent transplant within 3 years; 6.4% died, 11.9% were removed from the list, and 7.0% were still waiting (Figure 7.5). The rate of deceased donor transplant among active pediatric wait-list candidates was 136 per 100 patient-years on the waiting list. Rates were highest for candidates aged younger than 1 year (267 per 100 patient-years on the waiting list) and lowest for candidates aged 11 years or older (87 per 100 patient-years on the waiting list) (Figure 7.6). Of note, transplant rates have been steadily increasing for candidates aged younger than 1 year; for older candidates, rates began to plateau in 2005 for candidates aged 11 years or older and in 2009 for candidates aged 1-10 years. Pretransplant mortality has decreased for all age groups, to 5.8 deaths per 100 wait-list years in 2010-2012 (Figure 7.7). The pretransplant mortality rate is highest for candidates aged younger than 1 year, at 25.4 deaths per 100 wait-list years in 2010-2012 (Figure 7.7).

TRANSPLANT

The number of deceased donor liver transplants peaked at 542 in 2008 and decreased to 473 in 2012. The number of living donor liver transplants decreased from a peak of 120 in 2000 to

52 in 2012 (Figure 7.8). Approximately 10% of liver transplant recipients in 2012 had undergone previous transplant (Figure 7.9). In 2012, 10.1% of pediatric liver transplants were part of a multi-organ transplant: 5.5% pancreas, 5.5% intestine, and 4.2% kidney (Figure 7.10). DCD donors are rarely used in pediatric liver transplant, accounting for less than 1% in 2012 (Figure 7.12). Considering the past decade of pediatric liver transplant, age, sex, and ethnic distributions of recipients have changed little (Figure 7.13). Cholestatic disease remains the leading cause (46.9%) of liver failure. In 2010-2012, 38.4% of recipients waited less than 30 days for transplant, and 16.4% waited 31 to 60 days. Almost 60% of liver transplant recipients were not hospitalized before transplant. Considering medical urgency status, 15.4% of recipients underwent transplant as status 1A and 15.2% as status 1B; 13.8% had a MELD/pediatric end-stage liver disease (PELD) score of 35 or higher. The most common score at time of transplant was 15 to 29 (28%). Most pediatric patients (63.7%) received a whole liver; split liver transplants increased only slightly from 13.1% of transplants in 2002 to 16.1% in 2012. The proportion of living donors declined from 17.5% in 2000-2002 to 11% in 2010-2012. ABO-incompatible liver transplant occurred in 2.7% of recipients in 2010-2012, similar to the earlier era 2000-2002.

IMMUNOSUPPRESSION AND OUTCOMES

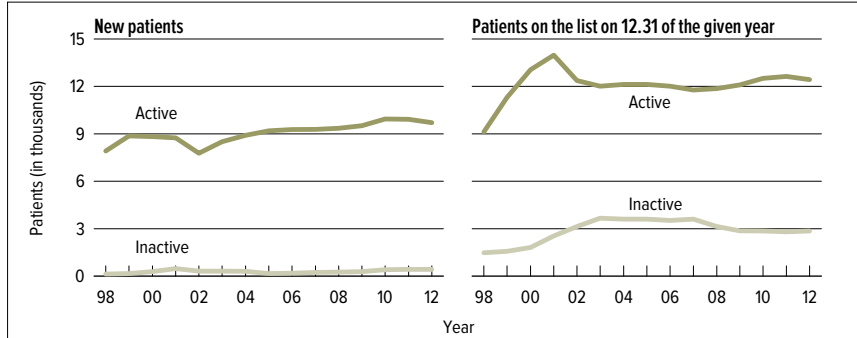
In 2012, 95.5% of pediatric liver transplant recipients were reported to receive tacrolimus as part of their initial maintenance immunosuppressive medication regimen, 89.2% to receive steroids, 46.5% to receive mycophenolate, and 1.2% to receive mTOR inhibitors (Figure 7.15). At 1 year after transplant, 53.8% of recipients were receiving steroids and 5.6% mTOR inhibitors. In 2012, 70% of liver transplants were performed with no induction immunosuppression. Graft survival has continued to improve over the past decade among recipients of deceased donor and living donor liver transplants. Graft survival for deceased donor transplants performed in 2012 was 92.8% at 30 days; for transplants in 2011, 87.3% at 1 year; for transplants in 2009, 82.0% at 3 years; for transplants in 2007, 78.7% at 5 years; and for transplants in 2002, 67.4% at 10 years (Figure 7.16). In contrast to other organs, graft survival is remarkably similar in the various age groups (Figure 7.19). The incidence of acute rejection increases with time

after transplant. Among liver transplant recipients from 2006 to 2011, 18% experienced acute rejection by 6 months after transplant, 27% by 12 months, and 33% by 24 months (Figure 7.18). Posttransplant lymphoproliferative disorder (PTLD) is a significant concern in pediatric transplant. The highest risk for PTLD occurs in Epstein-Barr virus (EBV)-negative recipients. The incidence of PTLD was 4.7% at 5 years after transplant in EBV-negative recipients and 3.4% among EBV-positive recipients (Figure 7.14).

Economics

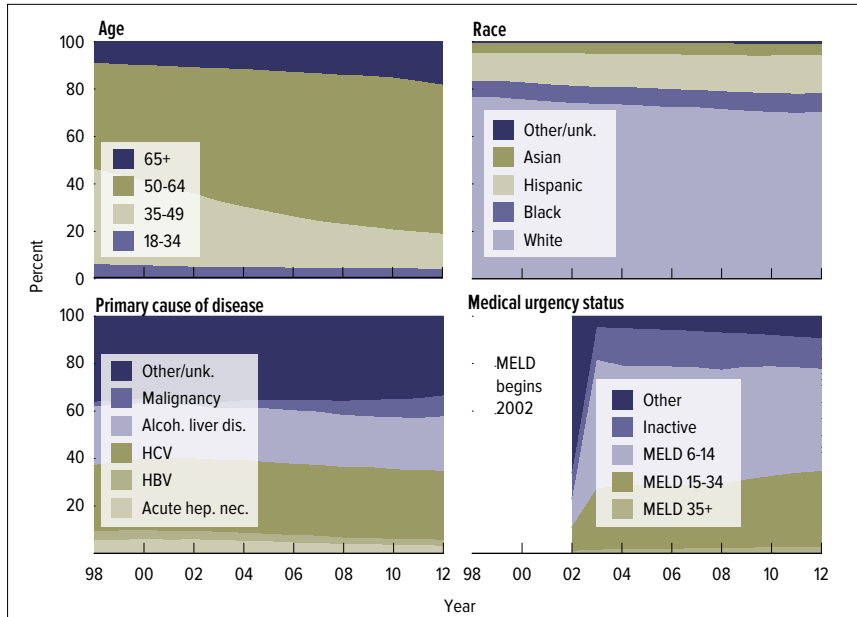
It may be surprising that Medicare is the largest single payer for liver transplant in the US, paying for some or all of the care for more than 30% of liver transplants in 2010 (Figure 8.1). Average reimbursement for liver recipients with primary Medicare coverage from transplant through 1 year after transplant was \$162,157 for Part A and \$25,447 for Part B (Figure 8.5), totaling \$187,604, approximately double the Medicare Parts A and B expenditure for a kidney transplant recipient (Figure 8.5, Kidney chapter) and approximately half the expenditure for a heart transplant recipient (Figure 7.5, Heart chapter). Rehospitalization is common after liver transplant; rates are relatively high in the first year (Figure 8.2) and drop by half in the second year (Figure 8.3). Primary causes of rehospitalization are dominated by surgical complications and infections in both the first and second years after transplant (Figure 8.4). Annual costs following the first year are dramatically smaller; Medicare Parts A and B costs average \$20,385 and \$10,240, respectively, during the second year (Figure 8.6), totaling \$30,625, and are expected to remain stable in later years. Additional costs not accounted for here include reimbursement to hospitals for the transplant portion of the Medicare Cost Report and Medicare Part D. Including estimates for these brings average Medicare cost to approximately \$250,000 in the first year after transplant and approximately \$35,000 in subsequent years, which is remarkably similar to total cost estimates for kidney and pancreas transplant. Liver transplant recipients account for 15% of all Medicare Parts A and B expenditures after solid organ transplant, \$597 million, or \$26,499 per patient in 2010 (Figure 8.7).

wait list



LI 1.1 Adult patients waiting for a liver transplant

Patients waiting for a transplant. A “new patient” is one who first joins the list during the given year, without having listed in a previous year. However, if a patient has previously been on the list, has been removed for a transplant, and has relisted since that transplant, the patient is considered a “new patient.” Patients concurrently listed at multiple centers are counted only once. Those with concurrent listings and active at any program are considered active; those inactive at all programs at which they are listed are considered inactive.



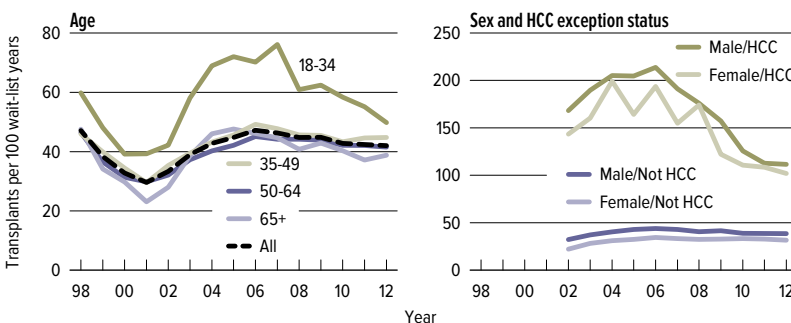
LI 1.2 Distribution of adult patients waiting for a liver transplant

Patients waiting for a transplant any time in the given year. Age determined on the earliest of listing date or December 31 of the given year. Concurrently listed patients are counted once. Malignancy as primary cause of disease includes, but is not limited to hepatocellular carcinoma (HCC); for some patients with HCC, another condition may have been cited as the primary cause of liver failure. Medical urgency status is the first known in the given year.

	Level	2002		2012		
		N	%	N	%	
Age	18-34	724	4.7	611	4.0	
	35-49	4,817	31.0	2,248	14.7	
	50-64	8,414	54.2	9,748	63.7	
	65+	1,577	10.2	2,701	17.6	
Sex	Male	8,986	57.9	9,485	62.0	
	Female	6,546	42.1	5,823	38.0	
Race	White	11,533	74.3	10,754	70.3	
	Black	1,012	6.5	1,081	7.1	
	Hispanic	2,207	14.2	2,593	16.9	
	Asian	678	4.4	745	4.9	
	Other/unk.	102	0.7	135	0.9	
Primary cause of disease	Acute hep. nec.	733	4.7	321	2.1	
	HBV	572	3.7	427	2.8	
	HCV	4,796	30.9	4,612	30.1	
	Alcoholic liver dis.	3,519	22.7	3,657	23.9	
	Cholestatic disease	1,784	11.5	1,307	8.5	
	Malignancy	289	1.9	1,052	6.9	
	Other/unk.	3,839	24.7	3,932	25.7	
	Tx history	Listed for first tx	14,557	93.7	14,903	97.4
	Listed for subseq. tx	975	6.3	405	2.6	
Blood type	A	5,510	35.5	5,771	37.7	
	B	1,727	11.1	1,679	11.0	
	AB	410	2.6	391	2.6	
	O	7,885	50.8	7,467	48.8	
Time on wait list	<1 year	4,632	29.8	5,565	36.4	
	1-2	3,577	23.0	2,818	18.4	
	2-3	2,571	16.6	1,809	11.8	
	3-4	1,762	11.3	1,171	7.6	
	4-5	1,082	7.0	936	6.1	
	5+	1,908	12.3	3,009	19.7	
Status	Active	12,395	79.8	12,442	81.3	
	Inactive	3,137	20.2	2,866	18.7	
Medical urgency status	1A/1B	-	0.0	2	0.0	
	MELD 35+	29	0.2	61	0.4	
	MELD 30-34	35	0.2	67	0.4	
	MELD 25-29	95	0.6	168	1.1	
	MELD 20-24	550	3.5	943	6.2	
	MELD 15-19	2,183	14.1	2,611	17.2	
	MELD 10-14	5,154	33.2	4,687	30.9	
	MELD 6-9	4,002	25.8	2,505	16.5	
	HCC T1	72	0.5	2	0.0	
	HCC T2	184	1.2	793	5.2	
	Other exceptions	74	0.5	447	3.0	
		Inactive	3,137	20.2	2,866	18.9
	Total		15,532	100.0	15,308	100.0

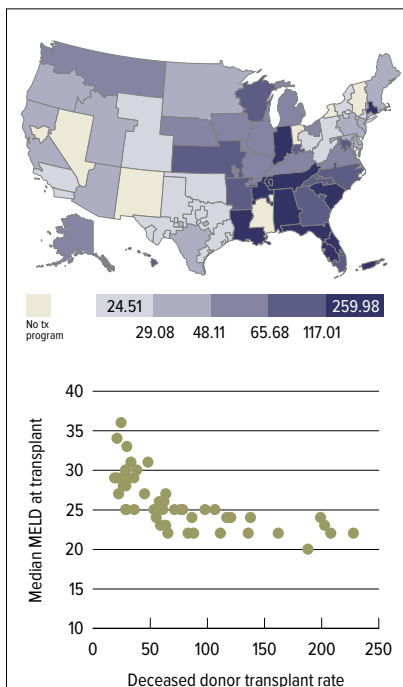
LI 1.3 Characteristics of adult patients on the liver transplant waiting list on December 31, 2002 & December 31, 2012

Patients waiting for a transplant on December 31, 2002 and December 31, 2012, regardless of first listing date; active/inactive status is on this date, and multiple listings are not counted.



LI 1.4 Deceased donor liver transplant rates among active adult waiting list candidates

Transplant rates are computed as the number of deceased donor transplants per 100 patient-years of active waiting time in a given year. Age is calculated on the first active listing date in a given year. HCC candidates are those with exception points granted in the given year.



LI 1.5 Deceased donor liver transplant rates per 100 patient years on the waiting list among active adult candidates, by DSA, 2011-2012

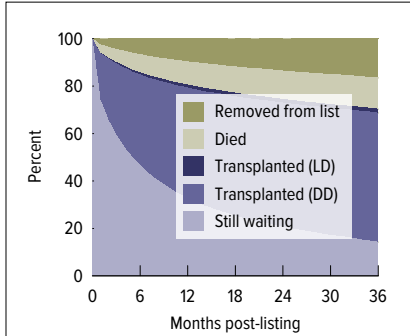
Transplant rates by DSA of the listing center, limited to those with active time on the waiting list in 2011 and 2012; deceased donor transplants only. Maximum time per listing is two years. Patients with concurrent listings in a single DSA are counted once in that DSA, and those listed in multiple DSAs are counted separately per DSA.

	2010	2011	2012
Patients at start of year	14,956	15,360	15,428
Patients added during year	10,349	10,359	10,143
Patients removed during year	9,925	10,272	10,281
Patients at end of year	15,380	15,447	15,290
Removal reason			
Deceased donor transplant	5,450	5,539	5,468
Living donor transplant	209	187	192
Patient died	2,458	2,506	2,187
Patient refused transplant	53	60	73
Improved, tx not needed	552	541	644
Too sick to transplant	362	482	815
Other	841	957	902

LI 1.6 Liver transplant waiting list activity among adult patients

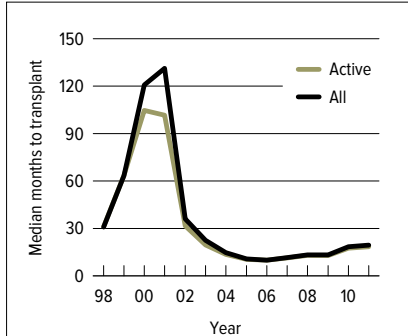
Patients with concurrent listings at more than one center are counted once, from the time of earliest listing to the time of latest removal. Patients listed, transplanted, and re-listed are counted more than once. Patients are not considered "on the list" on the day they are removed. Thus, patient counts on January 1 may be different from patient counts on December 31 of the prior year. Patients listed for multi-organ transplants are included. Known deaths following removal for being too ill are counted as deaths.

wait list



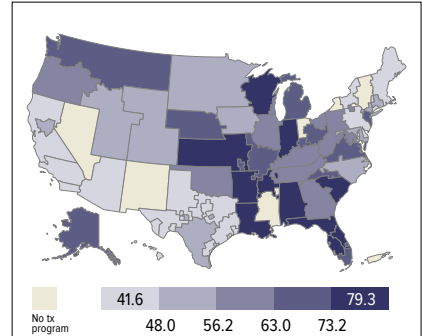
LI 1.7 Three-year outcomes for adult patients waiting for a liver transplant among new listings in 2009

Adult patients waiting for any liver transplant and first listed in 2009. Patients with concurrent listings at more than one center are counted once, from the time of the earliest listing to the time of latest removal.



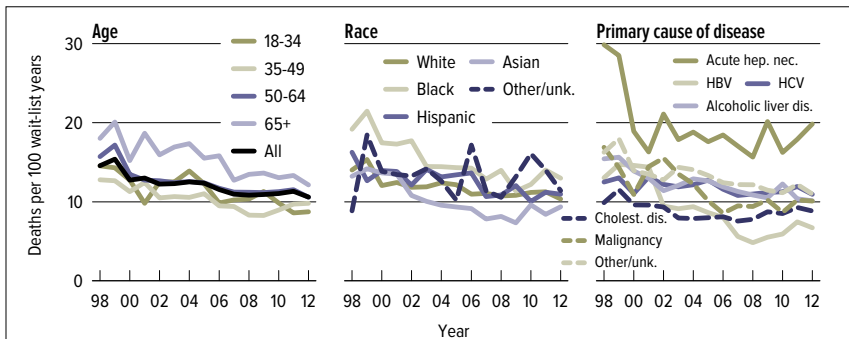
LI 1.8 Median months to liver transplant for wait-listed adult patients

Patients waiting for a transplant, with observations censored at December 31, 2012; Kaplan-Meier methods used to estimate time to transplant. If an estimate is not plotted, 50% of the cohort listed in that year had not been transplanted at the censoring date. Only the first transplant is counted.



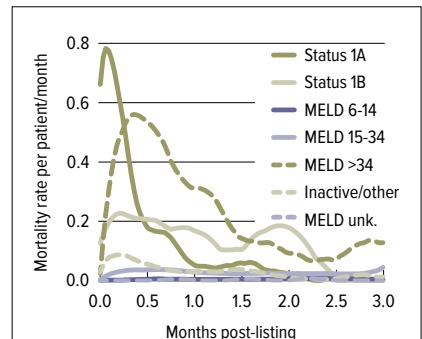
LI 1.9 Percent of adult wait-listed patients, 2007, who received a deceased donor liver transplant within five years, by DSA

Patients with concurrent listings in a single DSA are counted once in that DSA, and those listed in multiple DSAs are counted separately per DSA.



LI 1.10 Pre-transplant mortality rates among adult patients wait-listed for a liver transplant

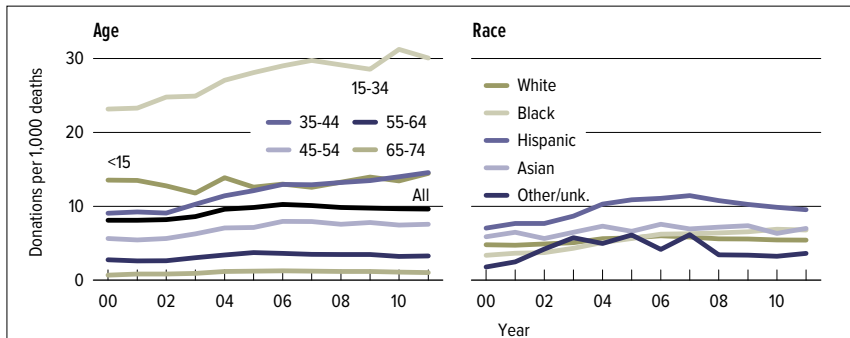
Patients waiting for a transplant. Mortality rates are computed as the number of deaths per 100 patient-years of waiting time in the given year. For rates shown by different characteristics, waiting time is calculated as the total waiting time in the year for patients in that group. Only deaths that occur prior to removal from the waiting list are counted. Age is calculated on the latest of listing date or January 1 of the given year. Other patient characteristics come from the OPTN Transplant Candidate Registration form.



LI 1.11 Mortality rates by medical urgency status, 2007–2012

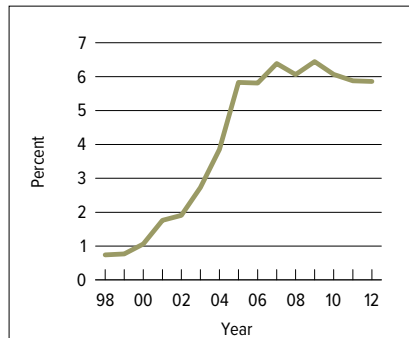
Estimated hazard rate for death among candidates waiting for a liver transplant by medical urgency status at listing. Epanechnikov kernel-smoothed estimators were used with a bandwidth of 0.5 for Status 1B candidates and 0.25 for all other status groups

deceased donation



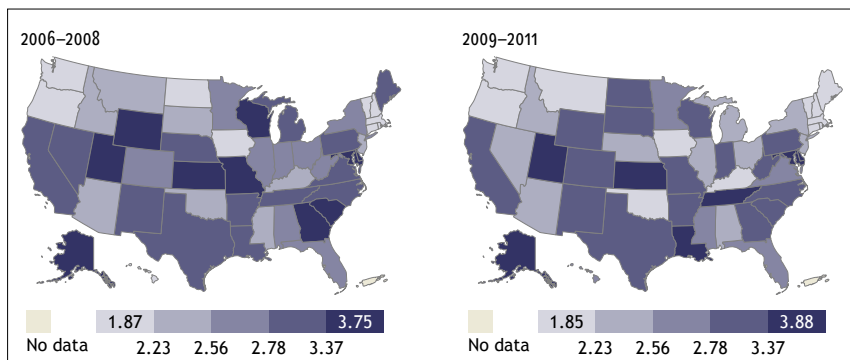
LI 2.1 Deceased donor liver donation rates

Numerator: Deceased donors age less than 75 with at least one liver recovered for transplant. Denominator: US deaths per year, age less than 75. (Death data available at <http://www.cdc.gov/nchs/products/nvsr.htm>.) Death data were available only through 2011.



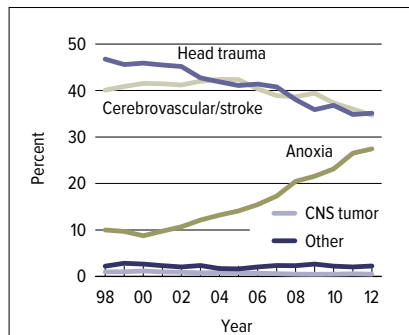
LI 2.4 Liver donors who are DCD

Deceased donors whose liver was recovered for transplant.



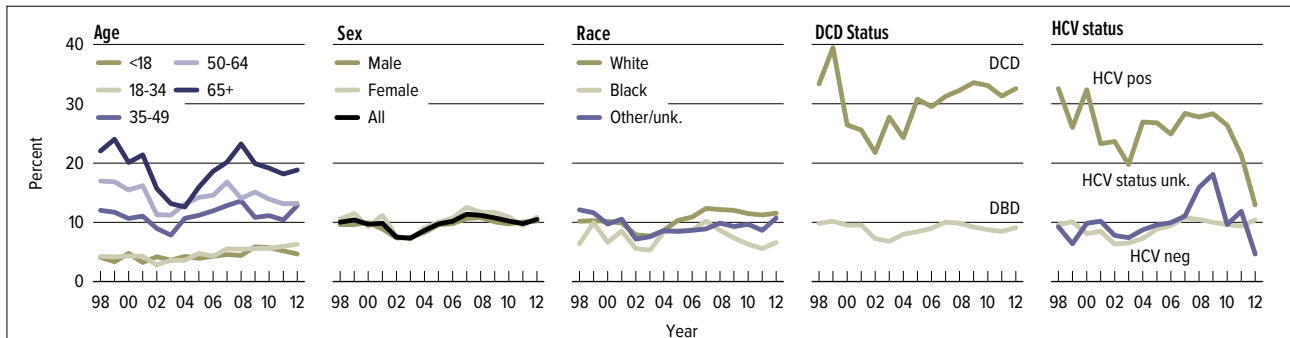
LI 2.2 Deceased donor liver donation rates (per 1,000 deaths), by state

Numerator: Deceased donors residing in the 50 states whose liver was recovered for transplant in the given year range. Denominator: US deaths by state during the given year range (death data available at <http://www.cdc.gov/nchs/products/nvsr.htm>). Rates are calculated within ranges of years for more stable estimates.



LI 2.5 Cause of death among deceased liver donors

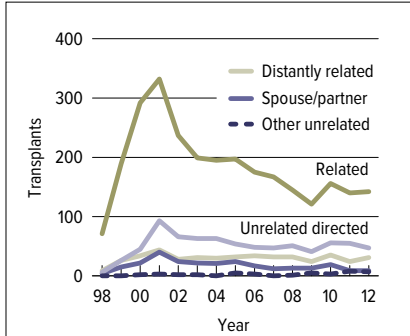
Deceased donors whose liver was transplanted. CNS = central nervous system.



LI 2.3 Discard rates for livers recovered for transplant

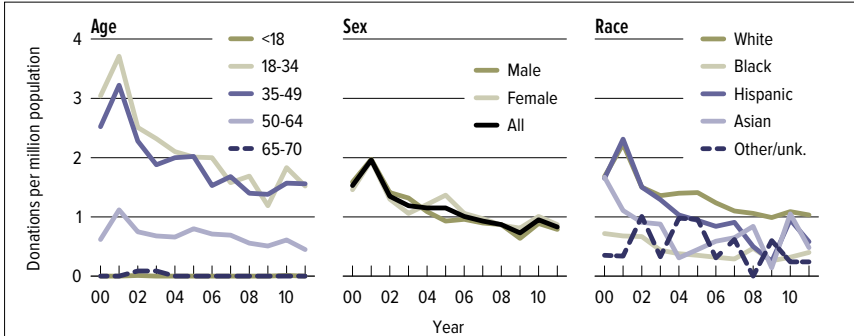
Percent of livers discarded out of all livers recovered for transplant.

live donation



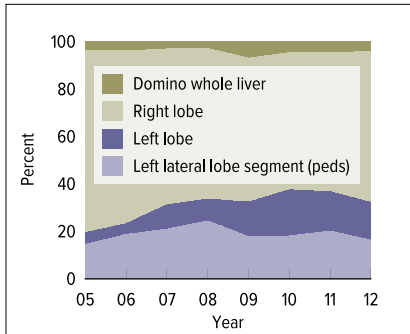
LI 3.1 Liver transplants from living donors, by donor relation

Number of living donor donations, excluding domino liver; characteristics recorded on the OPTN Living Donor Registration form.



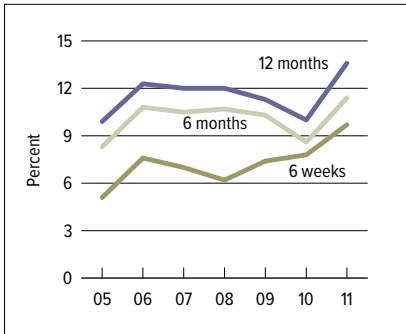
LI 3.2 Living donor liver donation rates

Number of living donors whose liver was recovered for transplant each year. Denominator: US population age 70 and younger (population data downloaded from http://www.cdc.gov/nchs/nvss/bridged_race/data_documentation.htm#vintage2011).



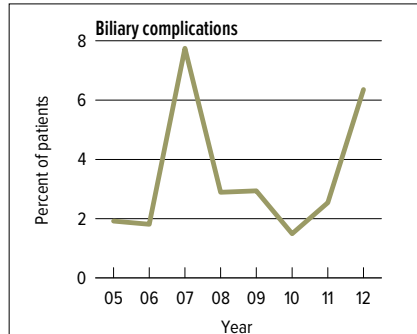
LI 3.3 Living donor liver transplant graft type

As reported on the OPTN Living Donor Registration form.

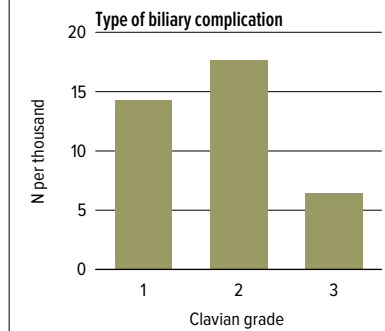


LI 3.4 Readmission to the hospital in the first 6 weeks, 6 months, and 1 year among living liver donors

Cumulative readmission to the hospital. The six-week time point is recorded at the earliest of discharge or six weeks post-donation.



Biliary complications



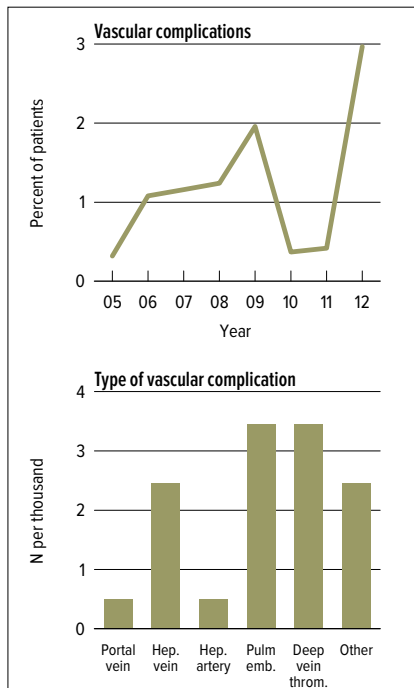
Type of biliary complication

LI 3.5 Biliary complications among living liver donors

Complications reported on the OPTN Living Donor Registration forms. Type of complication is shown among all living donors, 2005–2011.

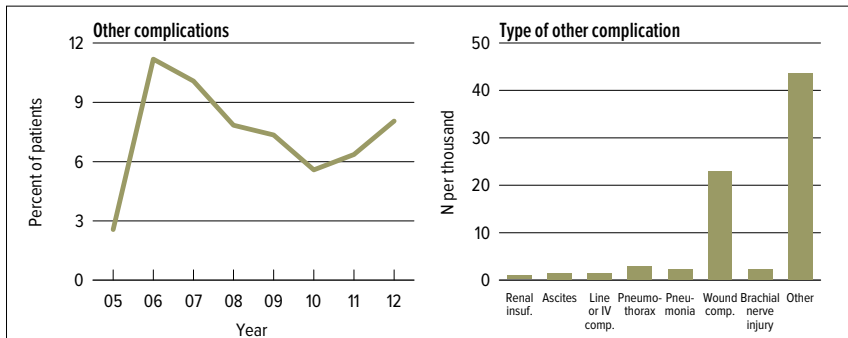
Clavian Grade 1: biliary JP drainage more than 10 days. Clavian Grade 2: interventional procedure (ERCP, PTC, percutaneous drainage, etc.). Clavian Grade 3: surgical intervention.

live donation



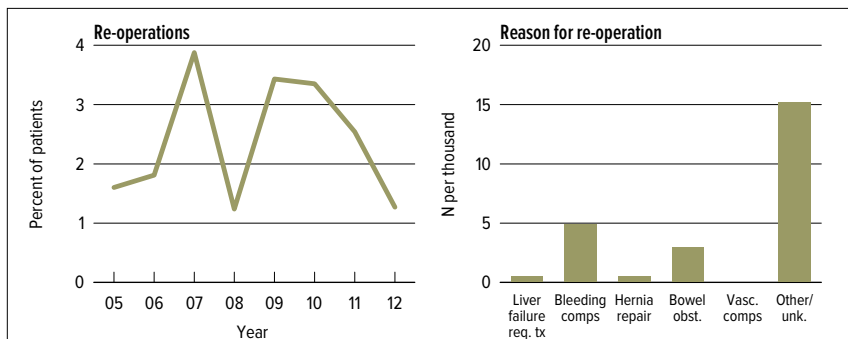
LI 3.6 Vascular complications requiring intervention among living liver donors

Complications reported on the OPTN Living Donor Registration forms. Type of complication is shown among all living donors, 2005–2012.



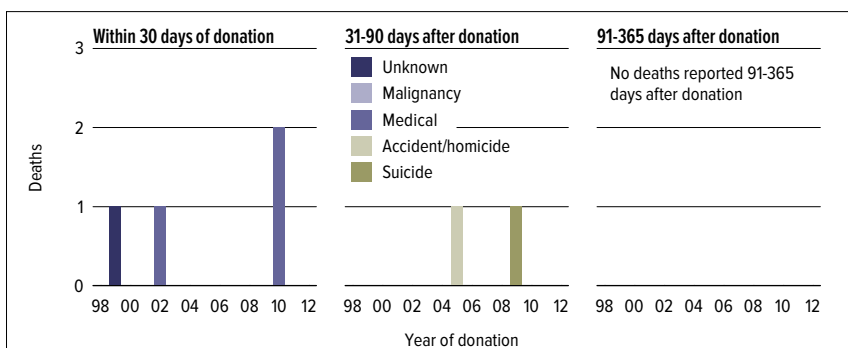
LI 3.7 Other complications requiring intervention among living liver donors

Complications reported on the OPTN Living Donor Registration forms. Type of complication is shown among all living donors, 2005–2012.



LI 3.8 Re-operation among living liver donors

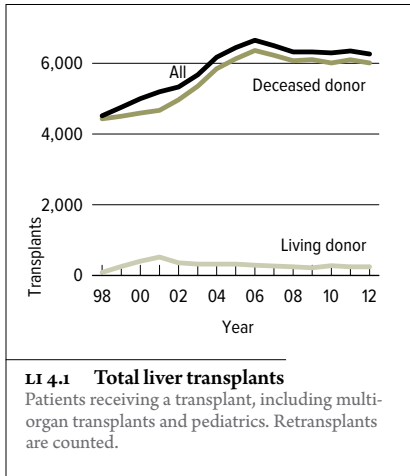
Complications reported on the OPTN Living Donor Registration forms. Type of complication is shown among all living donors, 2005–2012.



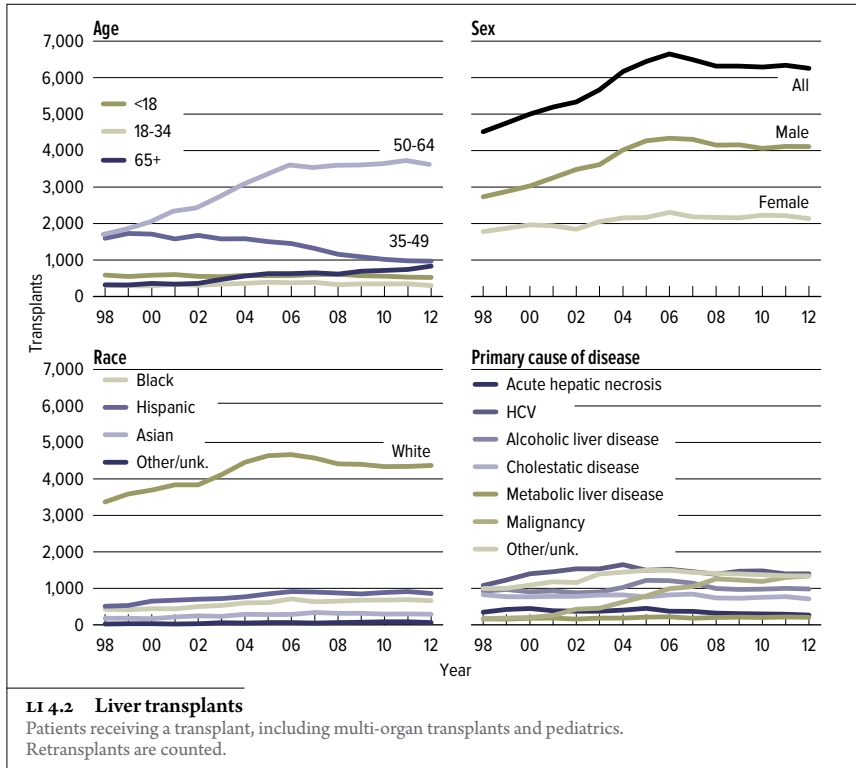
LI 3.9 Living liver donor deaths

Living liver donors; domino donors excluded. Deaths as reported to the OPTN or Social Security Administration. “Donation related” deaths are included in the “Medical” category.

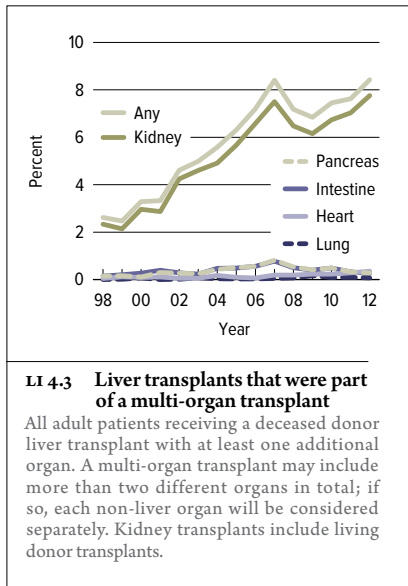
transplant



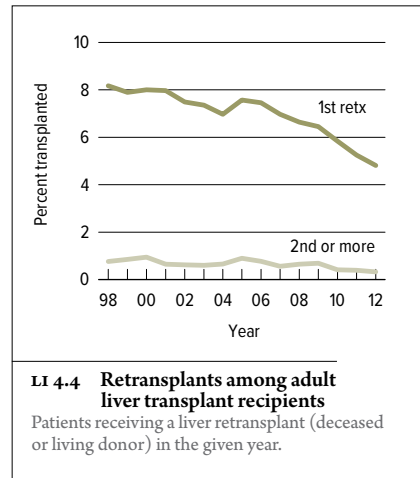
LI 4.1 Total liver transplants
Patients receiving a transplant, including multi-organ transplants and pediatrics. Retransplants are counted.



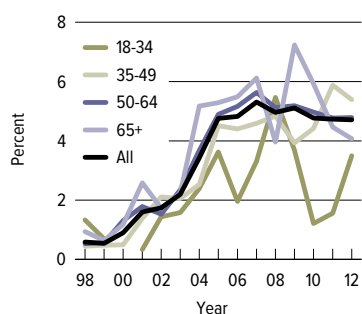
LI 4.2 Liver transplants
Patients receiving a transplant, including multi-organ transplants and pediatrics. Retransplants are counted.



LI 4.3 Liver transplants that were part of a multi-organ transplant
All adult patients receiving a deceased donor liver transplant with at least one additional organ. A multi-organ transplant may include more than two different organs in total; if so, each non-liver organ will be considered separately. Kidney transplants include living donor transplants.

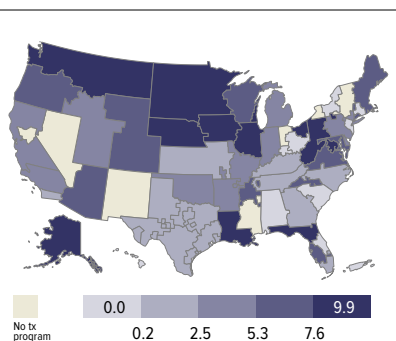


LI 4.4 Retransplants among adult liver transplant recipients
Patients receiving a liver retransplant (deceased or living donor) in the given year.



LI 4.5 Use of DCD livers among adult recipients, by recipient age

Percent of deceased donor transplants using a DCD donor. DCD = donation after circulatory death.



LI 4.6 Percent of adult, deceased donor liver transplants that are DCD, by DSA, 2010-2012

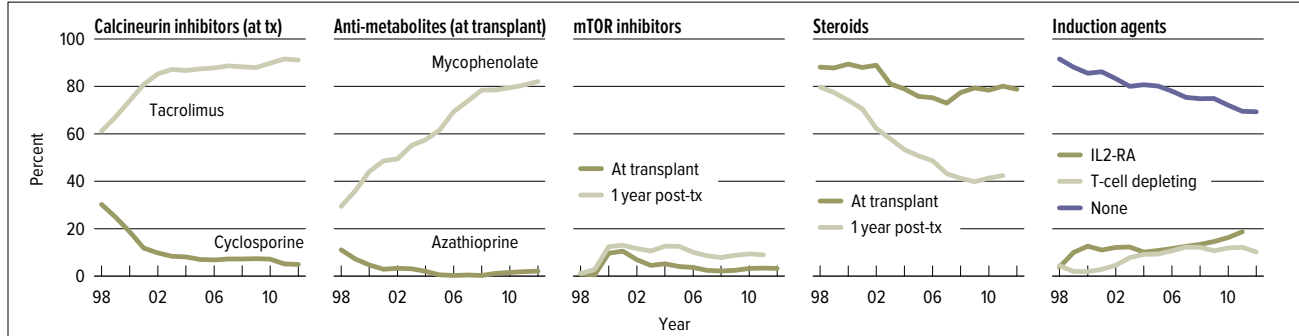
Percent of deceased-donor transplants using a DCD donor, by DSA of the transplanting center. Patients with concurrent listings in a single DSA are counted once in that DSA, and those listed in multiple DSAs are counted separately per DSA.

Level	2002		2012		
	N	%	N	%	
Age	18-34	306	6.4	303	5.3
	35-49	1,675	35.1	970	16.9
	50-64	2,433	50.9	3,623	63.2
	65+	363	7.6	835	14.6
	All				
Sex	Female	1,556	32.6	1,862	32.5
	Male	3,221	67.4	3,869	67.5
Race	White	3,536	74.0	4,088	71.3
	Black	400	8.4	576	10.1
	Hispanic	589	12.3	752	13.1
	Asian	225	4.7	260	4.5
	Other/unknown	27	0.6	55	1.0
Primary cause of disease	Acute hepatic necrosis	307	6.4	210	3.7
	HCV	1,531	32.0	1,402	24.5
	Alcoholic liver disease	883	18.5	986	17.2
	Cholestatic disease	535	11.2	458	8.0
	Metabolic liver disease	114	2.4	135	2.4
	Malignancy	369	7.7	1,281	22.4
	All others	1,038	21.7	1,259	22.0
Blood type	A	1,895	39.7	2,155	37.6
	B	610	12.8	796	13.9
	AB	262	5.5	277	4.8
	O	2,010	42.1	2,503	43.7
	All				
Time on waiting list	<30 days	1,308	27.4	1,723	30.1
	31-60 days	508	10.6	577	10.1
	61-90 days	334	7.0	394	6.9
	3-<6 months	694	14.5	899	15.7
	6-<12 months	786	16.5	906	15.8
	1-<2 years	680	14.2	706	12.3
	2-<3 years	265	5.5	213	3.7
	3+ years	195	4.1	313	5.5
	Missing/unknown	7	0.1	0	0.0
BMI	<18.5	120	2.5	115	2.0
	18.5-24.9	1,537	32.2	1,656	28.9
	25.0-29.9	1,694	35.5	1,928	33.6
	30.0-34.9	941	19.7	1,299	22.7
	35.0-39.9	321	6.7	525	9.2
	40.0+	121	2.5	206	3.6
Medical condition	Hospitalized: ICU	619	13.0	723	12.6
	Hospitalized: not ICU	722	15.1	1,074	18.7
	Not hospitalized	3,436	71.9	3,879	67.7
	Unknown	0	0.0	55	1.0
Medical urgency status before transplant	Status 1A/1B	296	6.2	192	3.4
	MELD 35-40	334	7.0	1,028	17.9
	MELD 30-34	365	7.6	920	16.1
	MELD 15-29	2,431	50.9	3,421	59.7
	MELD 6-14	610	12.8	169	2.9
	Other/unknown	741	15.5	1	0.0
Primary payer	Private	3,220	67.4	3,179	55.5
	Medicaid	603	12.6	718	12.5
	Other	954	20.0	1,834	32.0
Procedure type	Whole liver	4,414	92.4	5,474	95.5
	Partial liver, rmdr not tx	290	6.1	189	3.3
	Split liver	73	1.5	68	1.2
Donor type	Deceased	4,487	93.9	5,537	96.6
	Living	290	6.1	194	3.4
Patient on life support	Yes	364	7.6	403	7.0
Previous abdominal surg.	Yes	1,740	36.4	2,484	43.3
Diabetes	Yes	870	18.2	1,412	24.6
Portal vein thrombosis	Yes	132	2.8	570	9.9
Incident tumor found at transplant	Yes	223	4.7	198	3.5
Spontaneous bacterial peritonitis (SBP)	Yes	348	7.3	523	9.1
Total		4,777	100.0	5,731	100.0

LI 4.7 Characteristics of adult liver transplant recipients, 2002 & 2012

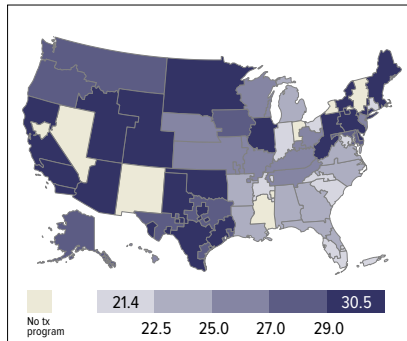
Patients receiving a transplant. Retransplants are counted.

transplant



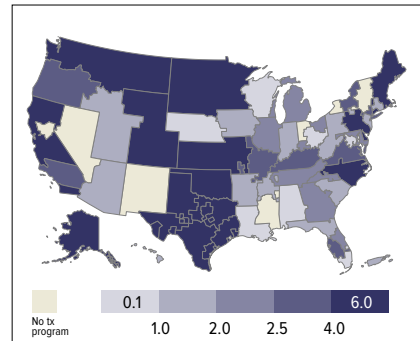
LI 4.8 Immunosuppression use in adult liver transplant recipients

One-year post-transplant data limited to patients alive with graft function one year post-transplant. Mycophenolate group includes mycophenolate mofetil and mycophenolate sodium.



LI 4.9 Median MELD score for adult, deceased donor liver transplants, by DSA, 2012

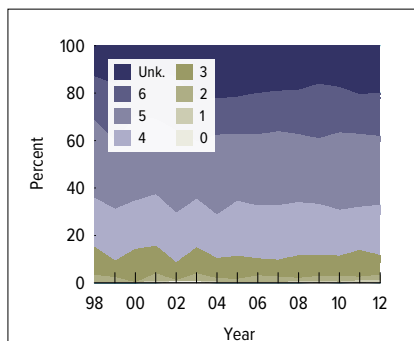
Deceased donor liver transplants; DSA of transplant center location. Patients with status 1A, 1B and inactive status excluded, and allocation MELD score used. Patients with concurrent listings in a single DSA are counted once in that DSA, and those listed in multiple DSAs are counted separately per DSA.



LI 4.10 Difference in lab MELD & allocation MELD among liver transplant recipients, 2012

Deceased donor liver transplants; DSA of transplant center location. Patients with status 1A, 1B and inactive status excluded. Patients with concurrent listings in a single DSA are counted once in that DSA, and those listed in multiple DSAs are counted separately per DSA.

donor-recipient matching



LI 5.1 Total HLA mismatches among adult liver-kidney transplant recipients

Donor and recipient antigen matching is based on the OPTN's antigen values and split equivalences policy as of 2012. Limited to liver-kidney transplants only.

RECIPIENT	DECEASED DONOR				LIVING DONOR			
	Neg.	Pos.	Unk.	Total	Neg.	Pos.	Unk.	Total
Negative	11.3	19.6	0.1	31.1	31.2	12.0	3.9	47.2
Positive	22.3	43.3	0.1	65.8	23.7	22.4	3.8	49.8
Unknown	1.0	2.2	0.0	3.2	1.6	1.2	0.3	3.0
Total	34.6	65.1	0.2	100	56.5	35.6	8.0	100

LI 5.2 Adult liver donor-recipient cytomegalovirus (CMV) serology matching, 2008–2012

Adult transplant cohort from 2008–2012. Donor serology is reported on the OPTN donor registration forms; recipient serology is reported on the OPTN recipient registration forms. Any evidence for a positive serology is taken to indicate that the person is positive for the given serology; if all fields are unknown, not done, or pending, the person is considered to be "unknown" for that serology; otherwise, serology is assumed negative.

RECIPIENT	DECEASED DONOR				LIVING DONOR			
	Neg.	Pos.	Unk.	Total	Neg.	Pos.	Unk.	Total
Negative	0.6	10.5	0.1	11.2	1.0	8.8	1.2	11.0
Positive	2.8	58.9	0.1	61.9	3.9	51.9	11.8	67.6
Unknown	1.1	25.7	0.1	26.9	1.6	8.5	11.4	21.4
Total	4.6	95.1	0.3	100	6.5	69.1	24.3	100

LI 5.3 Adult liver donor-recipient Epstein-Barr virus (EBV) serology matching, 2008–2012

Adult transplant cohort from 2008–2012. Donor serology is reported on the OPTN donor registration forms; recipient serology is reported on the OPTN recipient registration forms. Any evidence for a positive serology is taken to indicate that the person is positive for the given serology; if all fields are unknown, not done, or pending, the person is considered to be "unknown" for that serology; otherwise, serology is assumed negative.

RECIPIENT	DECEASED DONOR				LIVING DONOR			
	Neg.	Pos.	Unk.	Total	Neg.	Pos.	Unk.	Total
Negative	68.7	2.9	0.0	71.6	70.5	1.4	7.7	79.6
Positive	18.7	2.0	0.0	20.7	11.8	0.7	1.3	13.7
Unknown	7.5	0.3	0.0	7.8	2.9	0.0	3.8	6.7
Total	94.8	5.1	0.1	100	85.1	2.1	12.8	100

LI 5.4 Adult liver donor-recipient hepatitis B core antibody (HBcAb) serology matching, 2008–2012

Adult transplant cohort from 2008–2012. Donor serology is reported on the OPTN donor registration forms; recipient serology is reported on the OPTN recipient registration forms. Any evidence for a positive serology is taken to indicate that the person is positive for the given serology; if all fields are unknown, not done, or pending, the person is considered to be "unknown" for that serology; otherwise, serology is assumed negative.

RECIPIENT	DECEASED DONOR				LIVING DONOR			
	Neg.	Pos.	Unk.	Total	Neg.	Pos.	Unk.	Total
Negative	90.8	0.0	0.1	90.9	83.3	0.0	7.5	90.7
Positive	4.8	0.0	0.0	4.8	2.4	0.0	0.3	2.6
Unknown	4.3	0.0	0.0	4.3	5.5	0.0	1.2	6.7
Total	99.9	0.0	0.1	100	91.1	0.0	8.9	100

LI 5.5 Adult liver donor-recipient hepatitis B surface antigen (HBsAg) serology matching, 2008–2012

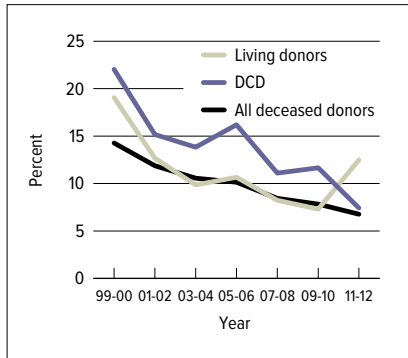
Adult transplant cohort from 2008–2012. Donor serology is reported on the OPTN donor registration forms; recipient serology is reported on the OPTN recipient registration forms. Any evidence for a positive serology is taken to indicate that the person is positive for the given serology; if all fields are unknown, not done, or pending, the person is considered to be "unknown" for that serology; otherwise, serology is assumed negative.

RECIPIENT	DECEASED DONOR				LIVING DONOR			
	Neg.	Pos.	Unk.	Total	Neg.	Pos.	Unk.	Total
Negative	52.9	0.1	0.0	53.0	58.8	0.4	6.5	65.8
Positive	39.6	3.2	0.0	42.8	26.7	0.3	2.7	29.7
Unknown	4.0	0.1	0.0	4.2	2.7	0.0	1.8	4.6
Total	96.6	3.4	0.0	100	88.2	0.7	11.1	100

LI 5.6 Adult liver donor-recipient hepatitis C serology matching, 2008–2012

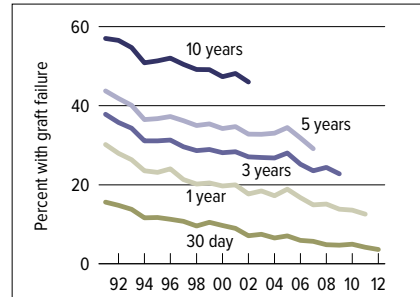
Adult transplant cohort from 2008–2012. Donor serology is reported on the OPTN donor registration forms; recipient serology is reported on the OPTN recipient registration forms. Any evidence for a positive serology is taken to indicate that the person is positive for the given serology; if all fields are unknown, not done, or pending, the person is considered to be "unknown" for that serology; otherwise, serology is assumed negative.

outcomes



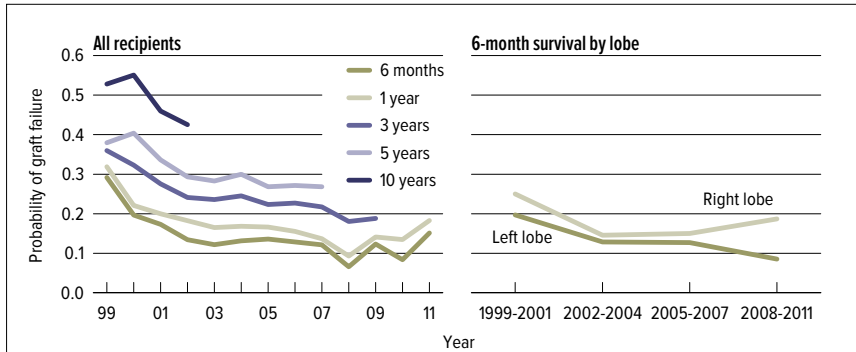
LI 6.1 Graft failure within the first 90 days after transplant among adult liver transplant recipients

All-cause graft failure is identified from multiple data sources, including the OPTN Transplant Recipient Registration form, OPTN Transplant Recipient Follow-up form, as well as death dates from the Social Security Administration. Transplants through September 30, 2012 are included to allow for sufficient follow-up.



LI 6.2 Graft failure among adult liver transplant recipients: deceased donor

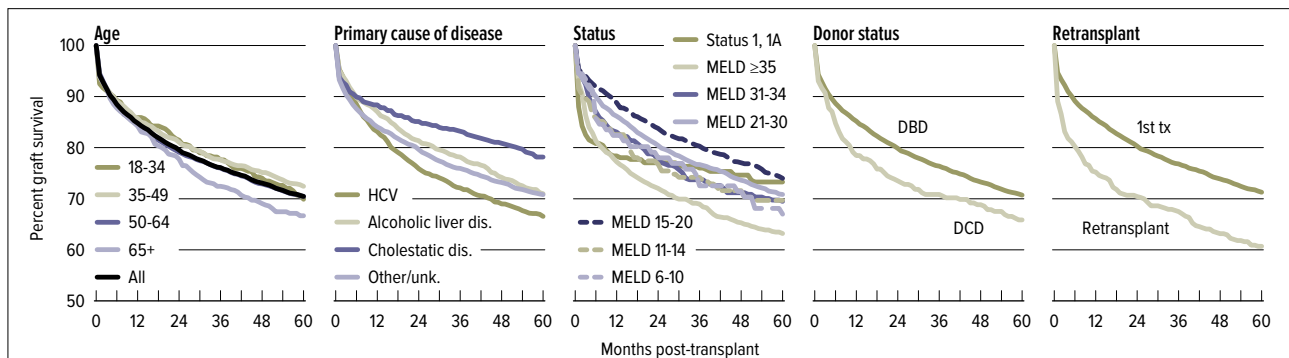
Cox proportional hazards models reporting probability, adjusting for age, sex, and race.



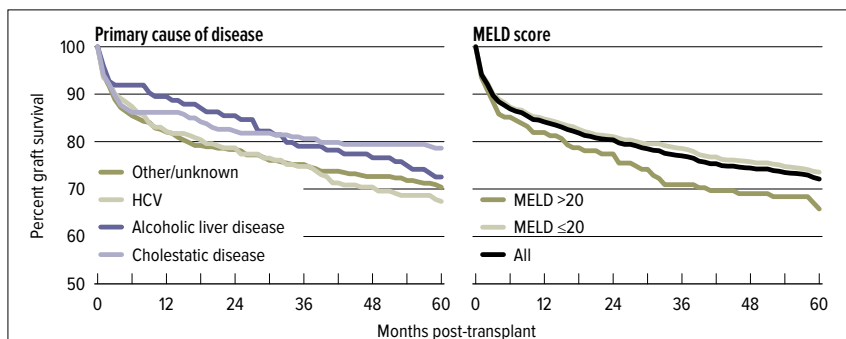
LI 6.3 Graft failure among adult liver transplant recipients: living donor

Cox proportional hazards models reporting probability, adjusting for age, sex, and race.

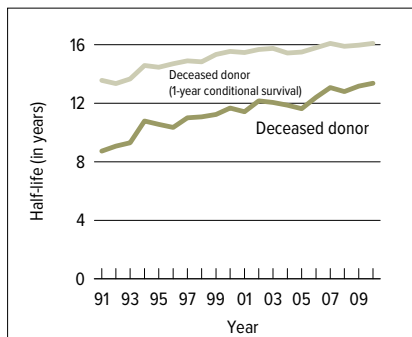
outcomes



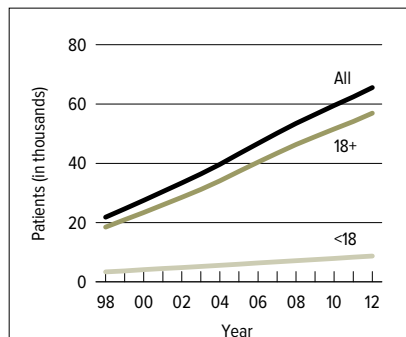
LI 6.4 Graft survival among adult liver transplant recipients transplanted in 2007: deceased donors
Graft survival estimated using unadjusted Kaplan-Meier methods.



LI 6.5 Graft survival among adult liver transplant recipients transplanted in 2003–2007: living donors
Graft survival estimated using unadjusted Kaplan-Meier methods.

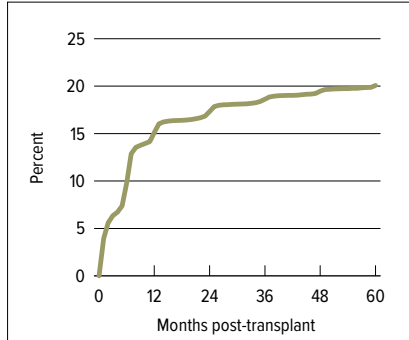


LI 6.6 Half-lives for adult, deceased donor liver transplant recipients
The half-life for a transplant cohort (e.g. 2009 liver transplants) is the time point in follow-up at which 50% of the transplanted grafts have failed. A conditional half-life for a transplant cohort is the same calculation but limited to those who survive with function at least 1 year post-transplant.



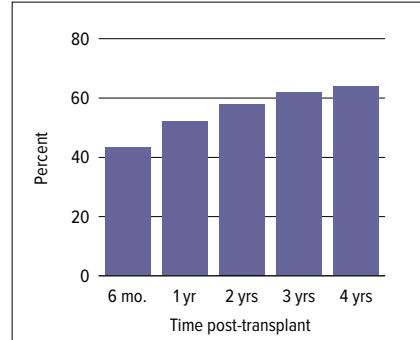
LI 6.7 Recipients alive & with a functioning liver transplant on June 30 of the year
Transplants before June 30 of the year that are still functioning. Patients are assumed alive with function unless a death or graft failure is recorded. A recipient can experience a graft failure and drop from the cohort, then be retransplanted and re-enter the cohort. Age cut is based on age at transplant.

outcomes



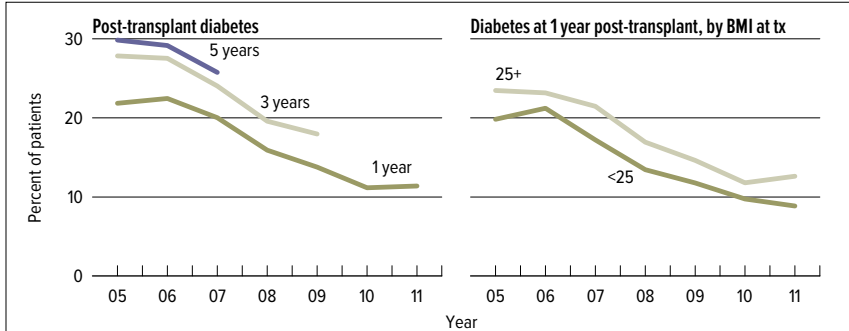
LI 6.8 Incidence of first acute rejection among adult patients receiving a liver transplant in 2006-2010

Acute rejection defined as a record of acute or hyperacute rejection, or a record of an anti-rejection drug being administered on either the Transplant Recipient Registration form or the Transplant Recipient Follow-up form. Only the first rejection event is counted. Cumulative incidence is estimated using Kaplan-Meier competing risk methods.



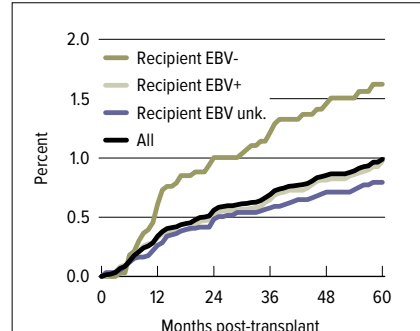
LI 6.9 Reported cumulative incidence of rehospitalizations among adult patients receiving a liver transplant in 2007-2012

Cumulative rate of rehospitalization; hospitalization identified from the OPTN Transplant Recipient Follow-up form. Patients required to be alive with graft function at each time period, so denominators reduce over time.



LI 6.10 Post-transplant diabetes among liver transplant recipients

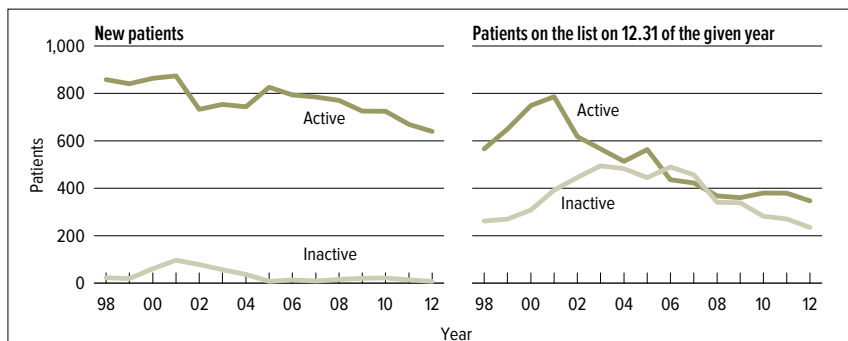
Percentage of adult deceased liver recipients who develop diabetes post-transplant out of patients who are diabetes free at transplant.



LI 6.11 Incidence of PTLD among adult patients receiving a liver transplant in 2006-2010, by recipient Epstein-Barr virus (EBV) status at transplant

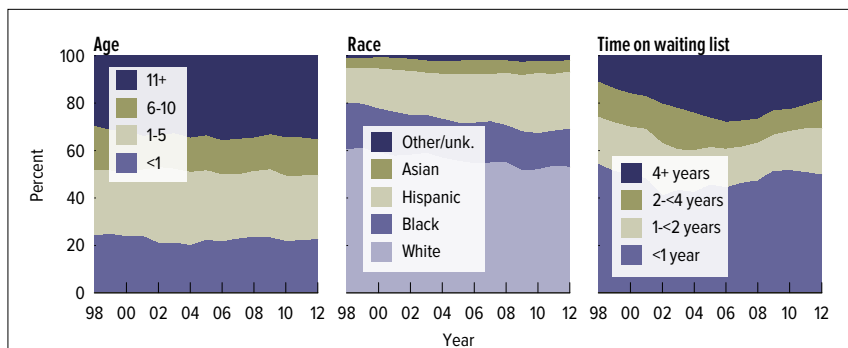
The cumulative incidence, is estimated using Kaplan-Meier competing risks methods. PTLD is identified as either a reported complication or cause of death on the Transplant Recipient Follow-up form or on the Post-transplant Malignancy form as polymorphic PTLD, monomorphic PTLD, or Hodgkin's Disease. Only the earliest date of PTLD diagnosis is considered.

pediatric transplant



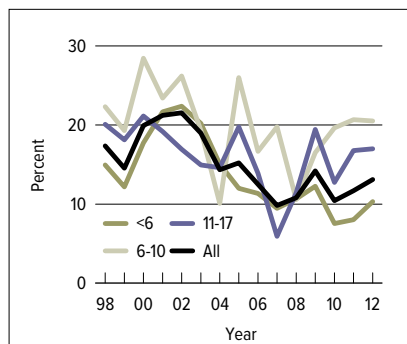
LI 7.1 Pediatric patients waiting for a liver transplant

Patients waiting for a transplant. A “new patient” is one who first joins the list during the given year, without having listed in a previous year. However, if a patient has previously been on the list, has been removed for a transplant, and has re-listed since that transplant, the patient is considered a “new patient.” Patients concurrently listed at multiple centers are counted only once. Those with concurrent listings and active at any program are considered active; those inactive at all programs at which they are listed are considered inactive.



LI 7.2 Distribution of pediatric patients waiting for a liver transplant

Patients waiting for a transplant any time in the given year. Age determined on the latest of listing date or January 1 of the given year. Concurrently listed patients are counted once.



LI 7.3 Prior liver transplant in pediatric patients waiting for a liver transplant, by age

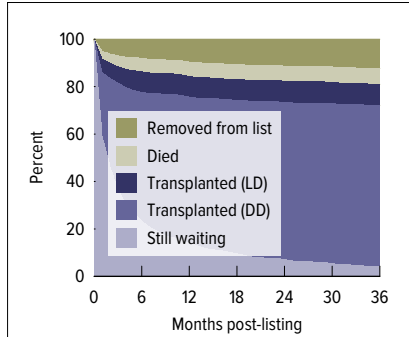
Prior transplant is obtained from the OPTN Transplant Candidate Registration form.

pediatric transplant

	2010	2011	2012
Patients at start of year	701	666	655
Patients added during year	747	684	648
Patients removed during year	781	696	718
Patients at end of year	667	654	585
Removal reason			
Deceased donor transplant	498	479	474
Living donor transplant	66	60	54
Patient died	63	33	37
Patient refused transplant	2	1	5
Improved, tx not needed	105	77	98
Too sick to transplant	12	12	17
Other	35	34	33

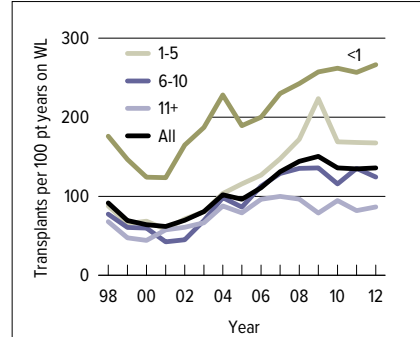
LI 7.4 Liver transplant waiting list activity among pediatric patients

Patients with concurrent listings at more than one center are counted once, from the time of earliest listing to the time of latest removal. Patients listed, transplanted, and re-listed, are counted more than once. Patients are not considered "on the list" on the day they are removed. Thus, patient counts on January 1 may be different from patient counts on December 31 of the prior year. Patients listed for multi-organ transplants are included.



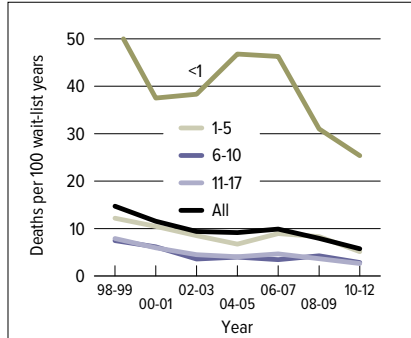
LI 7.5 Three-year outcomes for pediatric patients waiting for a liver transplant among new listings in 2009

Patients waiting for a transplant and first listed in 2009. Patients with concurrent listings at more than one center are counted once, from the time of the earliest listing to the time of latest removal.



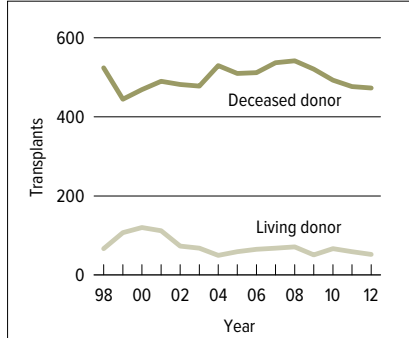
LI 7.6 Liver transplant rates among active pediatric waiting list candidates, by age

Transplant rates are computed as the number of deceased donor transplants per 100 patient-years of active waiting time in the given year. Age is calculated on the first active listing date in a given year.



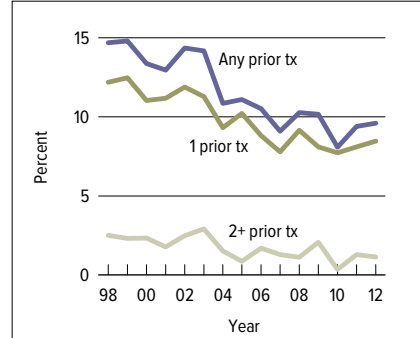
LI 7.7 Pre-transplant mortality rates among pediatric patients wait-listed for a liver transplant, by age

Patients waiting for a transplant. Mortality rates are computed as the number of deaths per 100 patient-years of waiting time in the given interval. Waiting time is calculated as the total waiting time per age group in the interval. Only deaths that occur prior to removal from the waiting list are counted. Age is calculated on the latest of listing date or January 1 of the given period.



LI 7.8 Pediatric liver transplants, by donor type

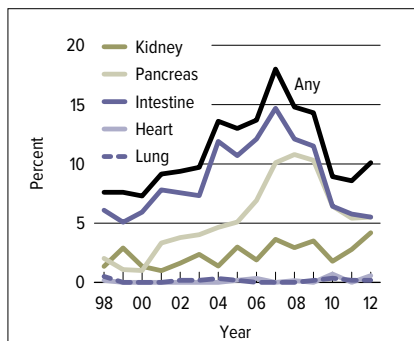
Patients receiving a liver transplant.



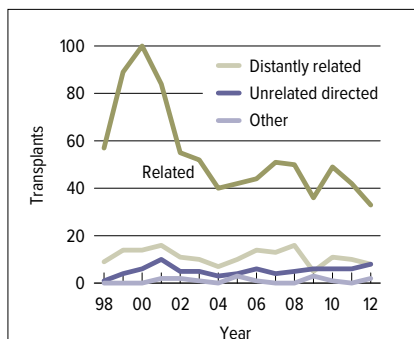
LI 7.9 Retransplants among pediatric liver transplant recipients

Includes patients transplanted after age 17, but listed at age 17 or younger. Retransplanted patients include only those with a prior transplant of the same type.

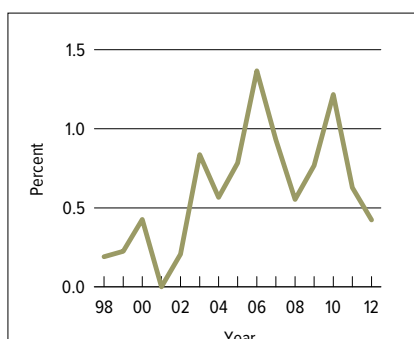
pediatric transplant



LI 7.10 Pediatric liver transplants that were part of a multi-organ transplant
 Patients receiving a deceased donor liver transplant with at least one additional organ. A multi-organ transplant may include more than two different organs in total; if so, each non-liver organ will be considered separately.



LI 7.11 Pediatric liver transplants from living donors
 Relationship of live donor to recipient is as indicated on the Living Donor Registration form.

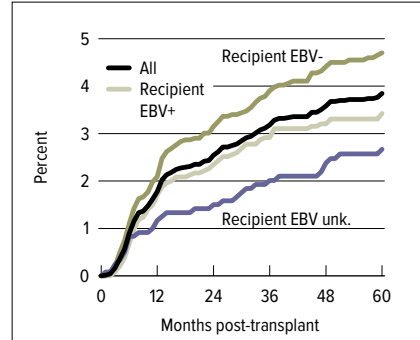


LI 7.12 Use of DCD donors in pediatric liver transplant recipients
 Patients receiving a DCD liver transplant.

Level	2000–2002		2010–2012			
	N	%	N	%		
Age	<1	497	28.5	462	28.5	
	1-5	621	35.6	587	36.2	
	6-10	214	12.3	228	14.1	
	11-17	414	23.7	344	21.2	
Sex	Female	938	53.7	833	51.4	
	Male	808	46.3	788	48.6	
Race	White	954	54.6	858	52.9	
	Black	324	18.6	267	16.5	
	Hispanic	378	21.6	356	22.0	
	Asian	79	4.5	103	6.4	
	Other/unknown	11	0.6	37	2.3	
Primary cause of disease	Acute hepatic necrosis	215	12.3	182	11.2	
	HCV	30	1.7	4	0.2	
	Cholestatic disease	749	42.9	761	46.9	
	Metabolic liver disease	155	8.9	224	13.8	
	Malignancy	192	11.0	211	13.0	
	All others	405	23.2	239	14.7	
	Transplant history	First transplant	1,505	86.2	1,476	91.1
Retransplant		241	13.8	145	8.9	
Blood type	A	603	34.5	530	32.7	
	B	252	14.4	215	13.3	
	AB	65	3.7	72	4.4	
	O	826	47.3	804	49.6	
Primary payer	Private	954	54.6	718	44.3	
	Medicaid	598	34.2	688	42.4	
	Other public	119	6.8	160	9.9	
	Other	75	4.3	55	3.4	
Time on wait list	<30 days	601	34.4	622	38.4	
	31-60 days	221	12.7	266	16.4	
	61-90 days	172	9.9	149	9.2	
	3-<6 months	270	15.5	266	16.4	
	6-<12 months	241	13.8	178	11.0	
	1-<2 years	125	7.2	91	5.6	
	2-<3 years	34	1.9	26	1.6	
	3+ years	42	2.4	22	1.4	
	No listing date	40	2.3	1	0.1	
	Medical condition	Hospitalized: ICU	568	32.5	365	22.5
		Hospitalized: not ICU	268	15.3	296	18.3
Not hospitalized		910	52.1	959	59.2	
Missing/Unknown		0	0.0	1	0.1	
Medical urgency status	1A	.	.	249	15.4	
	1B	.	.	247	15.2	
	MELD/PELD 35+	.	.	223	13.8	
	MELD/PELD 30-34	.	.	216	13.3	
	MELD/PELD 15-29	.	.	454	28.0	
	MELD/PELD < 15	.	.	229	14.1	
	Other/unknown	.	.	3	0.2	
Procedure type	Whole liver	1062	60.8	1,032	63.7	
	Partial liver, rest not tx	455	26.1	328	20.2	
	Split liver	229	13.1	261	16.1	
	Unknown	0	0.0	0	0.0	
Donor type	Deceased	1,441	82.5	1,443	89.0	
	Living	305	17.5	178	11.0	
Previous abdom. surgery	Yes	872	49.9	878	54.2	
Portal vein thrombosis	Yes	64	3.7	84	5.2	
Incident. tumor found at tx	Yes	8	0.5	8	0.5	
Spon. bac. peritonitis (SBP)	Yes	52	3.0	34	2.1	
ABO	Compatible or identical	1,701	97.4	1,577	97.3	
	Incompatible	45	2.6	44	2.7	
All patients		1,746	100.0	1,621	100.0	

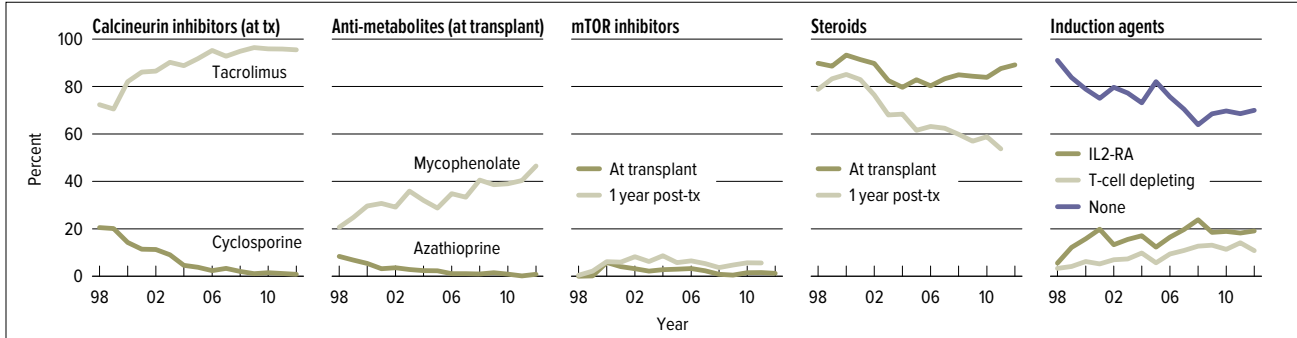
LI 7.13 Characteristics of pediatric liver transplant recipients, 2000–2002 & 2010–2012
 Patients receiving a transplant. Retransplants are counted. MELD / PELD began in 2002.

pediatric transplant



LI 7.14 Incidence of PTLD among pediatric patients receiving a liver transplant, 2000–2010, by recipient Epstein-Barr virus (EBV) status at transplant

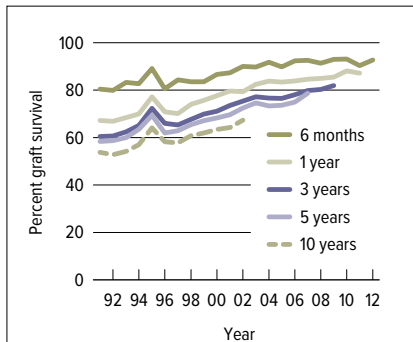
The cumulative incidence is estimated using Kaplan-Meier competing risks methods. PTLD is identified as either a reported complication or cause of death on the Transplant Recipient Follow-up form or on the Post-transplant Malignancy form as polymorphic PTLD, monomorphic PTLD, or Hodgkin's Disease. Only the earliest date of PTLD diagnosis is considered.



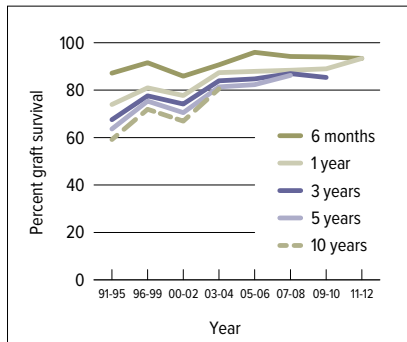
LI 7.15 Immunosuppression use in pediatric liver transplant recipients

One-year post-transplant data limited to patients alive with graft function one year post-transplant. Mycophenolate group includes mycophenolate mofetil and mycophenolate sodium.

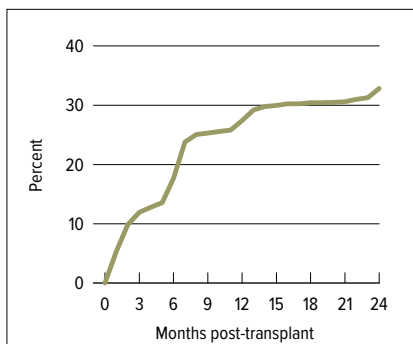
pediatric transplant



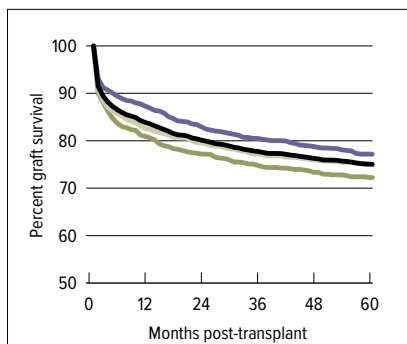
LI 7.16 Graft survival among pediatric liver transplant recipients: deceased donor
 Estimates computed with Cox proportional hazards model, adjusted for age, sex, and race.



LI 7.17 Graft survival among pediatric liver transplant recipients: living donor
 Estimates computed with Cox proportional hazards model adjusted for age, sex, and race.

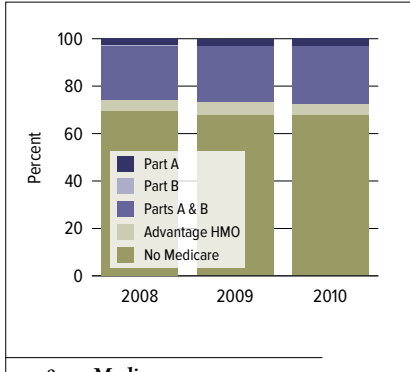


LI 7.18 Incidence of first acute rejection among pediatric patients receiving a liver transplant in 2006–2011
 Acute rejection defined as a record of acute or hyperacute rejection, or a record of an anti-rejection drug being administered on either the Transplant Recipient Registration form or the Transplant Recipient Follow-up form. Only the first rejection event is counted. Cumulative incidence, defined as the probability of acute rejection at any time prior to the given time, is estimated using Kaplan-Meier competing risk methods.



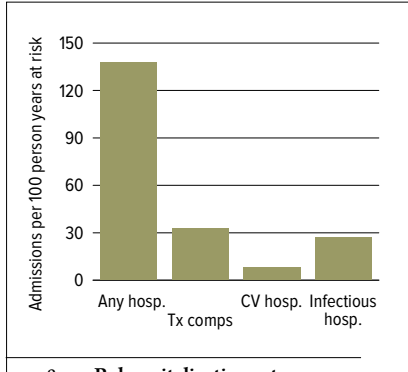
LI 7.19 Graft survival among pediatric liver transplant recipients transplanted in 2003–2007: deceased donors
 Graft survival estimated using unadjusted Kaplan-Meier methods.

Medicare data



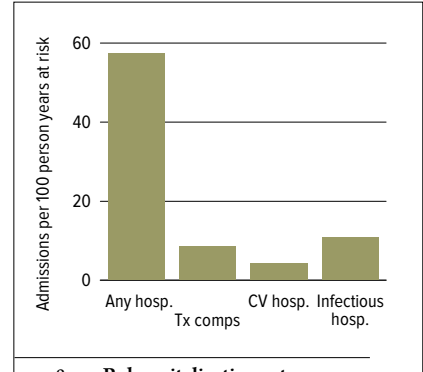
LI 8.1 Medicare coverage among liver transplant recipients

Coverage at the time of transplant as identified by the Medicare Beneficiary Annual Summary supplied by CMS.



LI 8.2 Rehospitalization rates among liver transplant recipients in the first post-transplant year

Transplant recipients, 2008, with Medicare as the primary payer at transplant. Rehospitalizations and reasons for rehospitalization determined from Medicare claims. First year rates are based on rehospitalizations occurring from initial discharge to one year later.



LI 8.3 Rehospitalization rates among liver transplant recipients in the second post-transplant year

Transplant recipients, 2008, with Medicare as the primary payer at transplant. Rehospitalizations and reasons for rehospitalization determined from Medicare claims. Second year rates are based on hospitalizations occurring from initial discharge+1 year to initial discharge+2 years.

Year 1 Cause of hospitalization	Percent of hospitalizations	Year 2 Cause of hospitalization	Percent of hospitalizations
Transplant complication	28.1	Transplant complication	18.1
Other	13.0	Gastro-intestinal	11.5
Other infection	11.6	Other	9.9
Gastro-intestinal	9.1	Other infection	8.8
Genito-urinary and breast	4.8	Genito-urinary and breast	7.3
Immune and Hhematologic	4.2	Skin and musculoskeletal	4.5
Electrolyte, acid-base & volume depletion	3.7	Respiratory infection	4.0
Bacteremia, viremia and septicemia	3.4	Immune and hematologic	4.0
Respiratory infection	3.2	Metabolic, endocrine, nutritional	3.8
Metabolic, endocrine, nutritional	2.8	Bacteremia, viremia & septicemia	3.5

LI 8.4 Top ten causes of rehospitalization among liver recipients transplanted in 2008 with Medicare primary coverage

Transplant recipients, 2008, with Medicare as the primary payer at transplant. Reasons for rehospitalization determined from Medicare claims, denominator for percentages includes only those re-hospitalized.

Medicare data

	# patients	Total costs		PPPY costs	
		Part A	Part B	Part A	Part B
All patients	2,226	321,013,987	50,376,613	162,157	25,447
Age					
0-11	*	*	*	*	*
12-17	*	*	*	*	*
18-34	59	8,525,181	1,329,656	158,098	24,658
35-49	306	45,367,415	7,230,266	170,079	27,106
50-64	1,163	165,706,546	25,690,236	158,519	24,576
65+	693	100,539,999	15,997,704	164,664	26,201
Sex					
Male	1,467	205,927,523	32,595,328	158,441	25,079
Female	759	115,086,464	17,781,286	169,260	26,151
Race					
White	1,537	216,645,202	34,462,220	158,953	25,285
Black	234	36,707,952	5,284,950	176,625	25,429
Hispanic	333	48,107,530	7,756,420	161,175	25,986
Asian/Pac. Isl.	100	16,651,937	2,376,311	184,695	26,357
Other/unk.	22	2,901,366	496,712	143,399	24,550
Primary cause of disease					
Acute hep. nec.	62	11,881,080	1,471,088	220,995	27,363
HBV	51	7,076,348	1,014,221	159,220	22,820
HCV	661	99,707,480	15,142,500	173,839	26,401
Alco. liver disease	386	53,006,877	8,406,637	151,912	24,093
Malignancy	287	35,765,011	6,070,074	135,309	22,965
Cholestatic dis.	195	29,024,359	4,507,489	170,591	26,493
Other/unk.	584	84,552,832	13,764,604	161,209	26,244

LI 8.5 Total and per-person per-year (PPPY) Medicare costs (\$) among liver transplant recipients in the first post-transplant year

Costs among recipients transplanted in 2008 and 2009 who had Medicare as the primary payer at the time of transplant. First year costs include the transplant hospitalization. Costs incurred after a transplant failure are excluded. Values for cells with 9 or fewer patients are suppressed.

	# patients	Total costs		PPPY costs	
		Part A	Part B	Part A	Part B
All patients	901	17,601,901	8,841,674	20,385	10,240
Age					
0-11	*	*	*	*	*
12-17	*	*	*	*	*
18-34	22	159,996	161,552	7,411	7,483
35-49	127	2,023,578	1,248,482	16,385	10,109
50-64	483	10,579,258	4,902,490	22,806	10,569
65+	267	4,793,386	2,514,049	18,985	9,957
Sex					
Male	585	10,718,295	5,587,032	19,193	10,005
Female	316	6,883,606	3,254,642	22,568	10,670
Race					
White	634	12,469,845	6,308,993	20,650	10,447
Black	82	2,242,840	837,614	28,049	10,475
Hispanic	134	2,211,934	1,351,120	16,728	10,218
Asian/Pac. Isl.	41	639,102	294,756	17,108	7,890
Other/unk.	10	38,179	49,192	3,807	4,906
Primary cause of disease					
Acute hep. nec.	28	375,950	202,251	13,787	7,417
HBV	19	238,143	121,625	12,500	6,384
HCV	247	5,946,784	2,468,917	25,393	10,542
Alco. liver disease	174	2,849,612	1,615,970	16,882	9,573
Malignancy	110	2,022,833	1,050,306	19,851	10,307
Cholestatic dis.	80	1,679,529	863,743	21,812	11,217
Other/unk.	243	4,489,051	2,518,861	19,082	10,707

LI 8.6 Total and per-person per-year (PPPY) Medicare costs (\$) among liver transplant recipients in the second post-transplant year

Costs among recipients transplanted in 2008 who had Medicare as the primary payer at the time of transplant. The second post-transplant year runs from 366 to 730 days after transplant. Costs incurred after a transplant failure are excluded. Values for cells with 9 or fewer patients are suppressed.

Medicare data

Total costs		2008 total costs			2009 total costs			2010 total costs		
		# patients	Part A	Part B	# patients	Part A	Part B	# patients	Part A	Part B
All patients		21,211	391,716,094	106,411,609	22,865	426,160,552	137,055,352	24,365	453,906,521	143,195,584
Age	0-11	75	2,219,698	473,923	77	2,220,116	503,599	88	2,494,070	652,442
	12-17	59	1,602,803	378,525	64	1,288,962	402,352	69	670,922	326,394
	18-34	864	15,373,334	3,881,979	907	16,512,642	5,045,785	955	18,611,775	5,325,707
	35-49	5,614	86,191,262	24,454,700	5,744	97,964,453	30,870,301	5,938	97,832,440	30,817,207
	50-64	11,661	210,685,697	57,157,300	12,818	220,515,882	72,296,815	13,837	243,154,740	76,799,362
	65+	2,938	75,643,300	20,065,181	3,255	87,658,497	27,936,500	3,478	91,142,574	29,274,472
Sex	Male	13,660	246,772,183	66,277,504	14,807	270,658,553	85,321,176	15,789	287,182,529	89,741,437
	Female	7,551	144,943,911	40,134,105	8,058	155,501,999	51,734,176	8,576	166,723,992	53,454,147
Race	White	16,304	283,825,238	80,185,940	17,424	302,009,851	101,716,758	18,477	327,816,618	106,467,904
	Black	1,546	39,026,215	8,109,682	1,730	42,987,954	10,884,473	1,900	48,131,500	12,100,417
	Hispanic	2,480	51,038,045	13,659,474	2,720	58,651,882	18,474,960	2,915	57,094,919	18,594,032
	Asian/Pacific Islander	736	14,844,170	3,652,742	831	20,031,072	5,113,957	877	16,696,382	4,860,874
	Other/unk.	145	2,982,427	803,772	160	2,479,793	865,205	196	4,167,102	1,172,357
Primary cause of disease	Acute hep. nec.	948	18,375,230	4,303,138	1,004	17,455,776	5,568,307	1,060	18,822,755	5,464,659
	HBV	622	10,170,925	2,612,558	664	12,157,520	3,500,814	697	10,097,232	3,376,485
	HCV	5,376	106,105,213	26,646,476	5,850	115,329,702	35,247,138	6,247	124,237,312	36,273,427
	Alco. liver disease	4,202	73,552,556	19,683,136	4,486	75,302,460	24,282,247	4,729	83,225,747	25,362,360
	Malignancy	975	24,529,998	5,751,010	1,288	30,197,857	8,749,112	1,518	33,901,209	10,034,446
	Cholestatic dis.	2,507	36,188,606	11,717,986	2,674	41,442,763	15,296,468	2,851	40,984,258	15,443,301
	Other/Unk.	6,581	122,793,566	35,697,306	6,899	134,274,474	44,411,267	7,263	142,638,009	47,240,907
Per person per year costs		2008 PPPY costs			2009 PPPY costs			2010 PPPY costs		
All patients		21,211	19,940	5,417	22,865	20,194	6,495	24,365	20,106	6,343
Age	0-11	75	30,796	6,575	77	30,439	6,905	88	29,015	7,590
	12-17	59	29,879	7,056	64	21,330	6,658	69	10,098	4,912
	18-34	864	18,837	4,757	907	19,395	5,927	955	20,664	5,913
	35-49	5,614	16,326	4,632	5,744	18,077	5,696	5,938	17,402	5,481
	50-64	11,661	19,481	5,285	12,818	18,585	6,093	13,837	18,898	5,969
	65+	2,938	28,990	7,690	3,255	30,934	9,859	3,478	30,039	9,648
Sex	Male	13,660	19,539	5,248	14,807	19,871	6,264	15,789	19,648	6,140
	Female	7,551	20,661	5,721	8,058	20,784	6,915	8,576	20,947	6,716
Race	White	16,304	18,742	5,295	17,424	18,753	6,316	18,477	19,106	6,205
	Black	1,546	27,897	5,797	1,730	27,486	6,959	1,900	27,884	7,010
	Hispanic	2,480	22,364	5,985	2,720	23,352	7,356	2,915	21,139	6,884
	Asian/Pacific Islander	736	21,598	5,315	831	25,921	6,618	877	20,511	5,971
	Other/unk.	145	22,361	6,026	160	16,602	5,792	196	23,563	6,629
Primary cause of disease	Acute hep. nec.	948	20,507	4,802	1,004	18,452	5,886	1,060	18,902	5,488
	HBV	622	17,234	4,427	664	19,402	5,587	697	15,086	5,045
	HCV	5,376	21,514	5,403	5,850	21,521	6,577	6,247	21,702	6,336
	Alco. liver disease	4,202	18,790	5,028	4,486	18,106	5,838	4,729	18,895	5,758
	Malignancy	975	29,344	6,880	1,288	27,046	7,836	1,518	25,356	7,505
	Cholestatic dis.	2,507	15,300	4,954	2,674	16,440	6,068	2,851	15,179	5,720
	Other/Unk.	6,581	20,093	5,841	6,899	21,063	6,967	7,263	21,149	7,004

LI 8.7 Total calendar-year Medicare costs (\$) spent on liver transplant recipients, 2008, 2009, & 2010

Costs paid by Medicare in each calendar year among recipients alive with graft function in the given year, regardless of Medicare eligibility at the time of transplant. Costs incurred after transplant failure are excluded.

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OPTN/SRTR 2012 Annual Data Report:

intestine

ABSTRACT Advances in the medical and surgical treatments of intestinal failure have led to a decrease in the number of transplants over the past decade. In 2012, 152 candidates were added to the intestinal transplant waiting list, a new low. Of these, 64 were listed for intestine-liver transplant and 88 for intestinal transplant alone or with an organ other than liver. Historically, the most common organ transplanted with the intestine was the liver; this practice decreased substantially from a peak of 52.9% in 2007 to 30.0% in 2012. Short-gut syndrome, which encompasses a large group of diagnoses, is the most common etiology of intestinal failure. The pretransplant mortality rate decreased dramatically over time for all age groups, from 51.0 per 100 wait-list years in 1998-1999 to 6.7 for patients listed in 2010-2012. Numbers of intestinal and intestine-liver transplants steadily decreased from 198 in 2007 to 106 in 2012. By age, intestinal transplant recipients have changed substantially; the number of adult recipients now approximately equals the number of pediatric recipients. Graft survival has improved over the past decade. Graft failure in the first 90 days after transplant occurred in 15.7% of 2011-2012 intestinal transplant recipients, compared with 21% in 2001-2002.

KEY WORDS Intestinal failure, intestinal transplant, liver-intestine transplant, waiting list.

(My husband) would have wanted nothing more than to give life to others even in his last days. We hum softly to the beat of the four organ recipients' hearts, praying that they are healthy and living with a renewed sense of purpose. We sing because we know he is dancing in heaven and he delights in our accompanying songs.

donor wife

Introduction

Advances in the medical and surgical treatments of intestinal failure have led to a decrease in the number of transplants over the past decade. Patient survival has improved, and morbidity associated with parenteral nutrition, including liver failure, has declined. Nevertheless, intestinal transplant still plays an important role in the treatment of intestinal failure. Intestinal transplants may be performed in isolation, with a liver transplant, or as part of a multi-visceral transplant including any combination of liver, stomach, pancreas, colon, spleen, and kidney.

WAITING LIST

The number of new patients added to the intestinal transplant waiting list continues to decrease, reaching a low of 152 in 2012. Of these patients, 64 were listed for intestine-liver transplant and 88 were listed for intestinal transplant alone or with an organ other than liver (Figure 1.1). Since 2008, prevalent wait-listed candidates for intestinal transplant outnumber those listed for intestine-liver transplant. Seventy-eight percent of the wait-listed candidates were active in 2012. Over the past decade, the age distribution of wait-listed candidates has shifted from being primarily pediatric to equal proportions of candidates aged less than 6 years (40.6%) and 18 years or older (39.2%) (Figure 1.2). The ethnicity distribution of candidates for intestinal transplant has not changed, nor has the cause-of-disease distribution. The most common etiology of intestinal failure remains short-gut syndrome (SGS), which encompasses a large group of diagnoses. In 2012, 47.8% of candidates were status 1; this proportion has steadily declined from a peak of 71.6% in 2002. Less than 10% of intestinal wait-listed candidates have previously undergone transplant. In 2012, 37.0% of candidates were on the waiting list for less than 1 year, 21.1% for 1 to less than 2 years, and 41.9% for 2 or more years (Figure 1.2). The causes of intestinal failure are similar among candidates listed for intestinal and intestine-liver transplant, though those listed for intestine-liver transplant are more likely to have more

congenital SGS and less likely to have “other SGS” (Figure 1.4). Rates of intestinal transplant and their trends vary by candidate age and dual intestine-liver listing. Among adults actively listed for intestine-liver transplant, transplant rates peaked in 2007 at 188 transplants per 100 wait-list years and declined to 44 by 2012 (Figure 1.5). Rates among adults waiting for intestinal transplant peaked in 2009 at 430 transplants per 100 wait-list years and fell to 157 by 2012. Rates for pediatric intestine-liver transplant have remained the most steady, ranging from 59 to 117 transplants per 100 wait-list years in 1998 to 2012. Transplant rates are lowest in pediatric intestinal candidates, with a rate of 32 transplants per 100 wait-list years in 2012 (Figure 1.5).

Among wait-listed candidates removed from the list in 2012, 60.7% were removed because they underwent deceased donor transplant, 15.6% were removed because their condition improved, and 11.6% died (Figure 1.6). Almost 70% of patients newly listed in 2009 underwent transplant within 3 years, 11.6% were removed from the list, 9.2% died and 12.4% were still waiting (Figure 1.7). For patients listed in 2011, median time to transplant has increased for pediatric candidates to 15.1 months (Figure 1.8). For the adult candidates, the median time to transplant was 4.0 months.

The pretransplant mortality rate has decreased dramatically over time for all age groups, from 51.0 per 100 wait-list years in 1998-1999 to 6.7 per 100 wait-list years for patients listed in 2010-2012 (Figure 1.9). However, pretransplant mortality is notably higher for intestine-liver transplant candidates than for intestinal transplant candidates (respectively, 14.2 vs. 1.5 deaths per 100 wait-list years in 2012) (Figure 1.9).

DONATION

The highest rate of deceased donor intestine donations has been from donors aged 5 to 14 years (Figure 2.1). The overall discard rate for donor intestines was 7.0% in 2012 (Figure 2.2). The most common cause of death among deceased intestine donors has been head trauma, 55.7% in 2012 (Figure 2.3).

TRANSPLANT

Numbers of intestinal and intestine-liver transplants steadily decreased from 198 in 2007 to 106 in 2012 (Figure 3.1). By age, intestinal transplant recipients have changed substantially; the number of adult recipients now approximately equals the number of pediatric recipients (Figure 3.2). Male recipients outnumber female recipients, and 64.2% of recipients in 2012 were white. Forty-four percent of deceased donor intestines were transplanted with another organ in 2012 (Figure 3.3). Historically, the most common organ transplanted with the intestine was the liver; this practice decreased substantially from a peak of 52.9% in 2007 to 30.0% in 2012.

In 2012, 11.3% of intestinal transplant recipients had previously undergone transplant (Figure 3.5). The highest proportion of retransplants in 2009-2012 was 29.8% in recipients aged 6 to 17 years (Figure 3.4). Over the past decade, the primary cause of intestinal failure has changed. The proportion of patients hospitalized in the intensive care unit before transplant has decreased, from 13.1% in 2002 to 2.8% in 2012; almost 90% of intestinal transplant recipients were not hospitalized before transplant in 2012, reflecting the improved general health of this population and the decreased number who require intestine-liver transplant (Figure 3.5).

IMMUNOSUPPRESSION

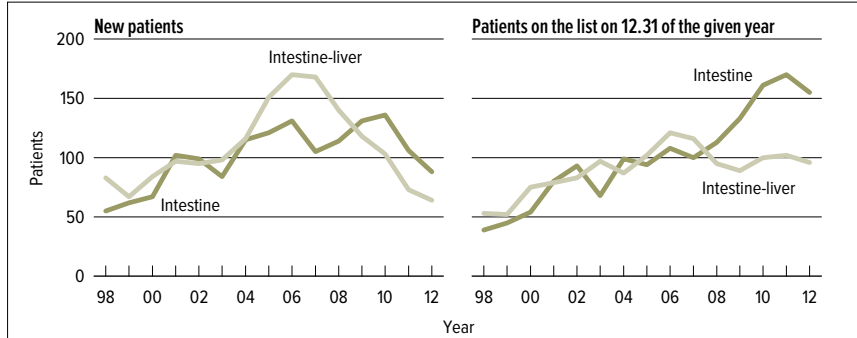
Among intestinal transplant recipients, the initial immunosuppression agents used most commonly in 2012 were tacrolimus (99.0%), steroids (66.0%), and mycophenolate (47.6%) (Figure 3.6). Initial use of mammalian target of rapamycin (mTOR) inhibitors were more rare (8.7%) (Figure 3.6). Steroids were used in 80.6% of recipients 1 year after transplant. For induction therapy, 52.4% received T-cell depleting agents, 14.6% received interleukin-2 receptor antagonists, and 33.0% received no induction.

OUTCOMES

Graft survival has improved over the past decade. Graft failure in the first 90 days after transplant occurred in 15.7% of 2011-

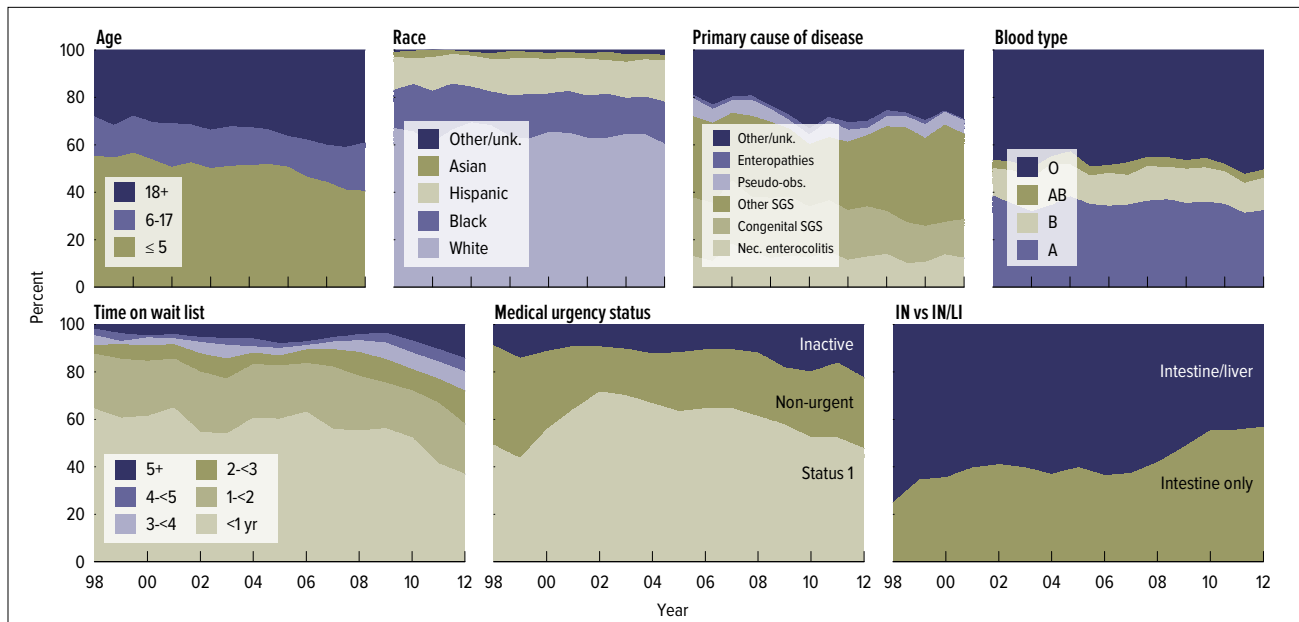
2012 intestinal transplant recipients, compared with 21% in 2001-2002 (Figure 4.1). For transplants in 2012, the graft failure rate was 6.2% at 30 days; in 2010-2011, 26.4% at 1 year; in 2008-2009, 49.9% at 3 years; in 2006-2007, 50.5% at 5 years; and in 2002-2003, 64.8% at 10 years (Figure 4.2). These numbers should be interpreted with caution, as they represent graft survival for two separate populations: recipients of intestine-liver transplants and recipients of intestinal transplants. Figure 4.3 shows graft survival by recipient age and organ transplanted. For patients undergoing intestinal transplant in 2007, 1- and 5-year graft survival was 69.2% and 53.8%, respectively, for recipients aged less than 18 years, and 74.2% and 48.3%, respectively, for recipients aged 18 years or older. One- and 5-year graft survival was 74.6% and 48.0%, respectively, among intestinal transplant recipients, and 68.6% and 53.7%, respectively, among intestine-liver recipients. Considering both recipient age and organ transplanted, adult recipients of intestinal transplants have the best 1-year graft survival (79.6%), and pediatric recipients of intestine-liver transplants have the best 5-year graft survival (56.3%). The number of recipients alive with a functioning intestinal graft has steadily increased since 1998, to 1004 in 2012 (Figure 4.4). For intestinal transplant recipients in 2005-2007, the 1-, 3-, and 5-year patient survival was 77.8%, 65.6%, and 63.4%, respectively (Figure 4.8). The incidence of first acute rejection increased over time after transplant; among recipients in 2006-2010, 39% experienced rejection in the first 12 months and 44% by 24 months (Figure 4.5). Rehospitalization is very common among intestinal transplant recipients, having occurred in 86.1% of 2007-2012 recipients by 6 months after transplant, and in almost all by 1 year after transplant (Figure 4.6). For patients who underwent transplant in 2006-2010, the incidence of posttransplant lymphoproliferative disorder among Epstein-Barr virus-negative recipients was 5.6% at 1 year, 7.6% at 2 years, 9.1% at 3 years, and 11.1% at 5 years (Figure 4.7).

wait list



IN 1.1 Patients waiting for an intestinal transplant

Patients waiting for a transplant. A “new patient” is one who first joins the list during the given year, without having listed in a previous year. However, if a patient has previously been on the list, has been removed for a transplant, and has relisted since that transplant, the patient is considered a “new patient.” Patients concurrently listed at multiple centers are counted only once. Those with concurrent listings and active at any program are considered active; those inactive at all programs at which they are listed are considered inactive.



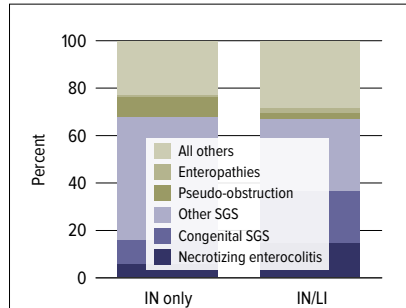
IN 1.2 Distribution of patients waiting for an intestinal transplant

Patients waiting for a transplant any time in the given year. Age determined on the earliest of listing date or December 31 of the given year. Concurrently listed patients are counted once. Medical urgency status is the first known in the given year.

	Level	2002		2012	
		N	%	N	%
Age	<6	92	52.3	107	42.5
	6-17	38	21.6	50	19.8
	18-34	15	8.5	20	7.9
	35-49	25	14.2	30	11.9
	50-64	5	2.8	40	15.9
	65+	1	0.6	5	2.0
Sex	Female	108	61.4	134	53.2
	Male	68	38.6	118	46.8
Race	White	126	71.6	150	59.5
	Black	26	14.8	46	18.3
	Hispanic	19	10.8	42	16.7
	Asian	4	2.3	8	3.2
	Other/unk.	1	0.6	6	2.4
Primary cause of disease	Necrotizing enterocolitis	24	13.6	30	11.9
	Congenital SGS	46	26.1	39	15.5
	Other SGS	49	27.8	86	34.1
	Pseudo-obstruction	9	5.1	15	6.0
	Enteropathies	1	0.6	2	0.8
	Other/unk.	47	26.7	80	31.8
Transplant history	Listed for first tx	164	93.2	230	91.3
	Listed for subseq tx	12	6.8	22	8.7
Blood type	A	61	34.7	78	31.0
	B	23	13.1	34	13.5
	AB	8	4.6	8	3.2
	O	84	47.7	132	52.4
Time on wait list	<1 yr	93	52.8	80	31.8
	1-<2	31	17.6	45	17.9
	2-<3	19	10.8	46	18.3
	3-<4	11	6.3	25	9.9
	4-<5	6	3.4	18	7.1
	5+	16	9.1	38	15.1
Medical urgency status	Status 1	100	56.8	100	39.7
	Non-urgent	40	22.7	77	30.6
	Inactive	36	20.5	75	29.8
IN vs LI/IN	LI/IN	83	47.2	96	38.1
	IN alone	93	52.8	156	61.9
Total		176	100.0	252	100.0

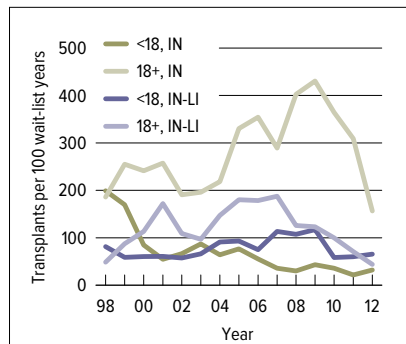
IN 1.3 Characteristics of patients on the intestinal transplant waiting list on December 31, 2002 & December 31, 2012

Patients waiting for a transplant on December 31, 2002 and December 31, 2012, regardless of first listing date; active/inactive status is on this date, and multiple listings are not counted.



IN 1.4 Cause of disease among patients on the intestinal transplant waiting list, 2008–2012, by IN vs. IN-LI

All candidates on the intestinal transplant waiting list.

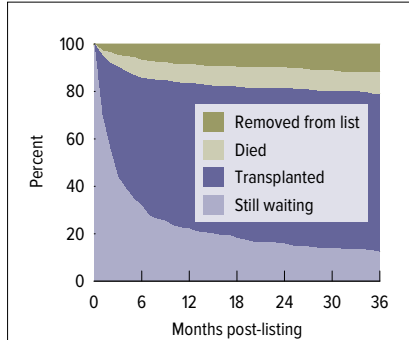


IN 1.5 Intestinal transplant rates among active waiting list candidates, by age

Transplant rates are computed as the number of deceased donor transplants per 100 patient-years of active waiting time in a given year. Age is calculated on the first active listing date in a given year.

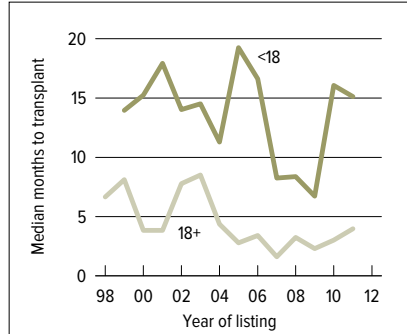
wait list

	2010	2011	2012
Patients at start of year	222	260	272
Patients added during year	239	179	152
Pts removed during year	200	167	173
Patients at end of year	261	272	251
Removal reason			
Deceased donor transplant	149	124	105
Living donor transplant	1	-	-
Patient died	18	24	20
Patient refused transplant	1	2	2
Improved, tx not needed	21	8	27
Too sick to transplant	5	3	3
Other	5	6	16



IN 1.7 Three-year outcomes for patients waiting for an intestinal transplant among new listings in 2009

All patients waiting for a transplant and first listed in 2009. Patients with concurrent listings at more than one center are counted once, from the time of the earliest listing to the time of latest removal.

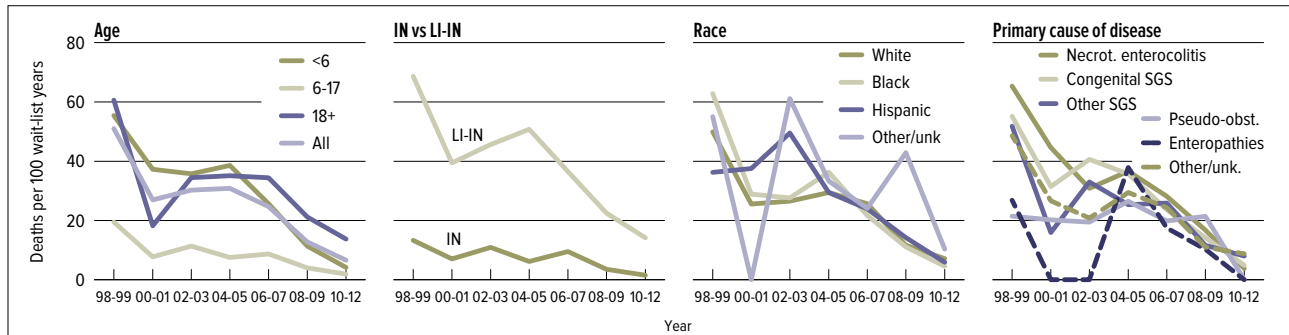


IN 1.8 Median months to intestinal transplant for wait-listed patients, by age

Patients waiting for a transplant, with observations censored at December 31, 2012; Kaplan-Meier method used to estimate time to transplant. If an estimate is not plotted, 50% of the cohort listed in that year had not been transplanted at the censoring date. Only the first transplant is counted.

IN 1.6 Intestinal transplant waiting list activity

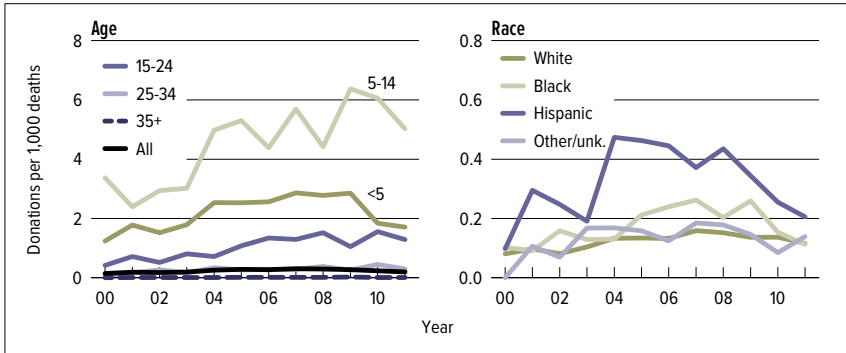
Patients with concurrent listings at more than one center are counted once, from the time of earliest listing to the time of latest removal. Patients listed, transplanted, and re-listed are counted more than once. Patients are not considered "on the list" on the day they are removed. Thus, patient counts on January 1 may be different from patient counts on December 31 of the prior year. Patients listed for multi-organ transplants are included. Known deaths following removal for being too ill are counted as deaths.



IN 1.9 Pre-transplant mortality rates among patients wait-listed for an intestinal transplant

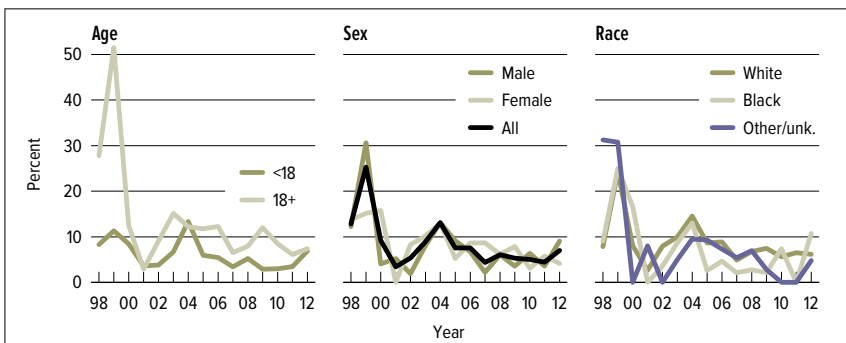
Patients waiting for a transplant. Mortality rates are computed as the number of deaths per 100 patient-years of waiting time in the given interval. For rates shown by different characteristics, waiting time is calculated as the total waiting time in the interval for patients in that group. Only deaths that occur prior to removal from the waiting list are counted. Age is calculated on the latest of listing date or January 1 of the given interval. Other patient characteristics come from the OPTN Transplant Candidate Registration form.

deceased donation



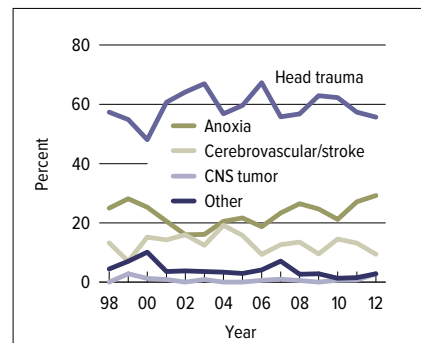
IN 2.1 Deceased donor intestinal donation rates

Numerator: Deceased donors age less than 75 with intestine recovered for transplant. Denominator: US deaths per year, age less than 75. (Death data available at <http://www.cdc.gov/nchs/products/nvsr.htm>.) Death data were available only through 2011.



IN 2.2 Discard rates for intestines recovered for transplant

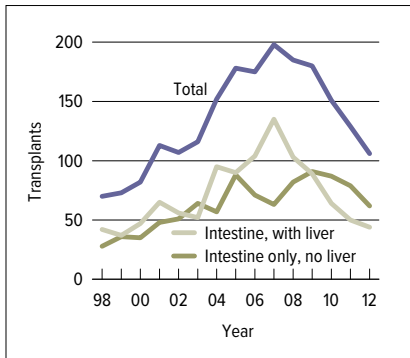
Percent of intestines discarded out of all intestines recovered for transplant.



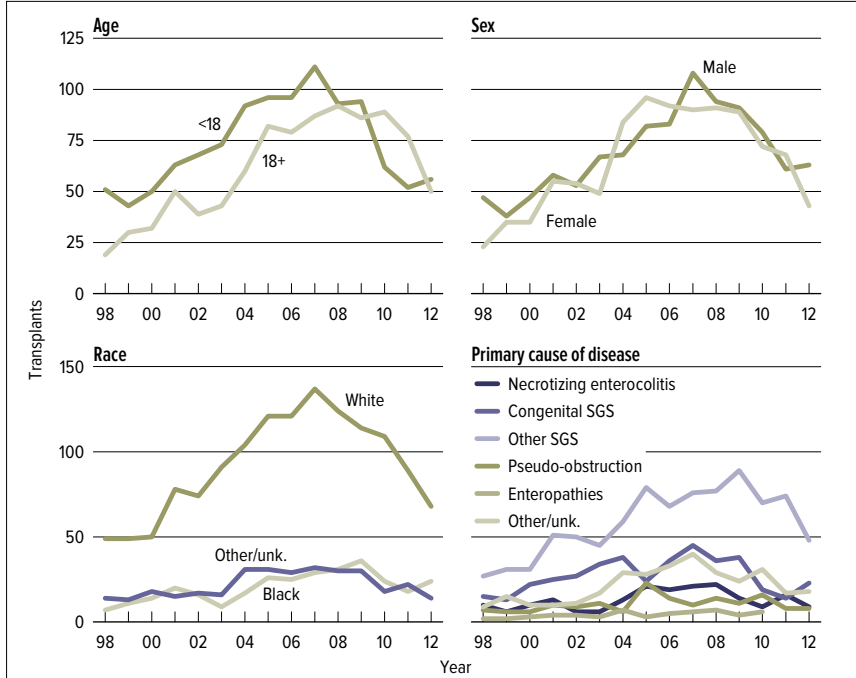
IN 2.3 Cause of death among deceased intestinal donors

Deceased donors whose intestine was transplanted. CNS = central nervous system.

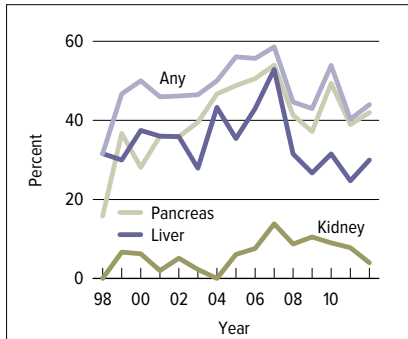
transplant



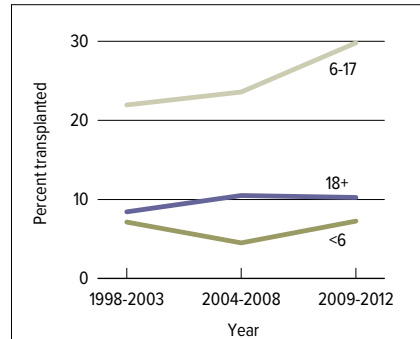
IN 3.1 Total intestinal transplants
Patients receiving a transplant, including multi-organ transplants and pediatric patients. Retransplants are counted.



IN 3.2 Intestinal transplants
Patients receiving a transplant, including multi-organ transplants and pediatric patients. Retransplants are counted.



IN 3.3 Intestinal transplants that were part of a multi-organ transplant
All adult patients receiving a deceased donor intestinal transplant with at least one additional organ. A multi-organ transplant may include more than two different organs in total; if so, each non-intestinal organ will be considered separately. Kidney transplants include living donor transplants.

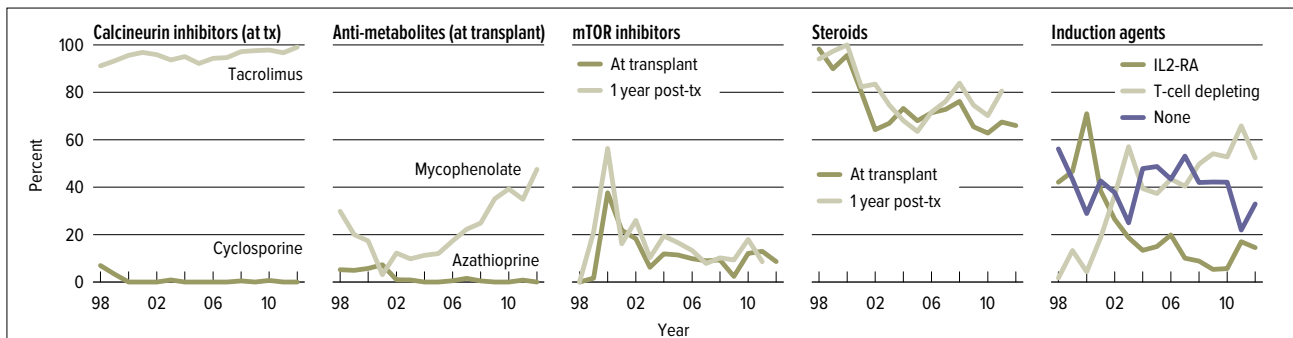


IN 3.4 Retransplants among intestinal transplant recipients
Patients receiving an intestinal retransplant in the given year.

	Level	2002		2012	
		N	%	N	%
Age	<18	68	63.6	56	52.8
	18-34	14	13.1	18	17.0
	35-49	15	14.0	12	11.3
	50-64	10	9.3	19	17.9
	65+	0	0.0	1	0.9
Sex	Female	54	50.5	43	40.6
	Male	53	49.5	63	59.4
Race	White	74	69.2	68	64.2
	Black	16	15.0	24	22.6
	Hispanic	16	15.0	12	11.3
	Asian	0	0.0	1	0.9
	Other/unknown	1	0.9	1	0.9
Primary cause of disease	Necrotizing enterocolitis	6	5.6	9	8.5
	Congenital SGS	27	25.2	23	21.7
	Other SGS	50	46.7	48	45.3
	Pseudo-obstruction	9	8.4	8	7.5
	Enteropathies	4	3.7	0	0.0
	Other/unk	11	10.3	18	17.0
Blood type	A	51	47.7	35	33.0
	B	11	10.3	13	12.3
	AB	9	8.4	6	5.7
	O	36	33.6	52	49.1
Time on waiting list	<30 days	21	19.6	22	20.8
	31-60 days	25	23.4	11	10.4
	61-90 days	6	5.6	12	11.3
	3-<6 months	27	25.2	22	20.8
	6-<12 months	15	14.0	16	15.1
	1-<2 years	8	7.5	13	12.3
	2-<3 years	3	2.8	6	5.7
	3+ years	2	1.9	4	3.8
Medical condition	Hospitalized: ICU	14	13.1	3	2.8
	Hospitalized: not ICU	30	28.0	9	8.5
	Not hospitalized	63	58.9	93	87.7
	Unknown	0	0.0	1	0.9
Primary payer	Private	54	50.5	44	41.5
	Medicaid	39	36.4	42	39.6
	Other	14	13.1	20	18.9
Donor type	Deceased	106	99.1	106	100.0
	Living	1	0.9	0	0.0
Intestine transplant history	First transplant	95	88.8	94	88.7
	Retransplant	12	11.2	12	11.3
Patient on life support	Yes	18	16.8	13	12.3
Total		107	100.0	106	100.0

IN 3.5 Characteristics of intestinal transplant recipients, 2002 & 2012

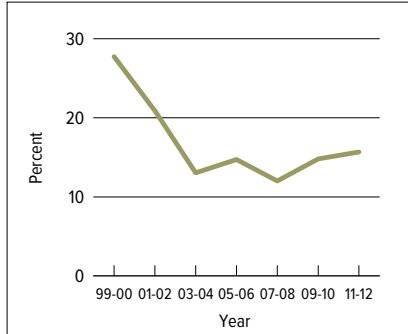
Patients receiving a transplant. Retransplants are counted.



IN 3.6 Immunosuppression use in intestinal transplant recipients

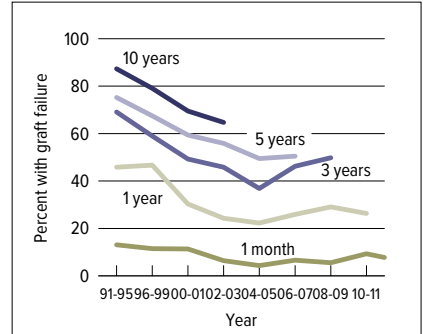
One-year post-transplant data limited to patients alive with graft function one year post-transplant. Mycophenolate group includes mycophenolate mofetil and mycophenolate sodium.

outcomes



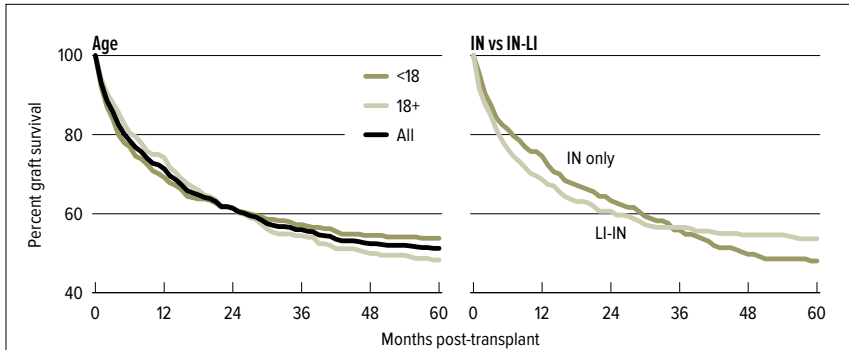
IN 4.1 Graft failure within the first 90 days among intestinal transplant recipients

All-cause graft failure is identified from multiple data sources, including the OPTN Transplant Recipient Registration form and the OPTN Transplant Recipient Follow-up form, as well as death dates from the Social Security Administration. Transplants through September 30, 2012 are included to allow for sufficient follow-up.



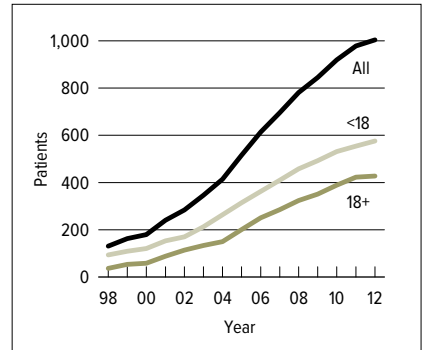
IN 4.2 Graft failure among intestinal transplant recipients: deceased donor

Cox proportional hazards models reporting probability, adjusting for age, sex, and race.



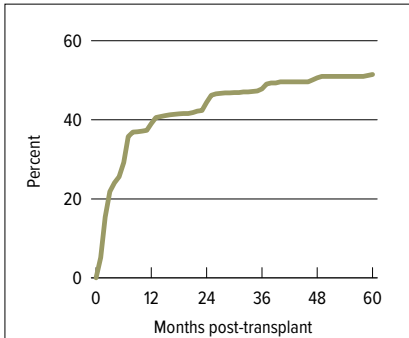
IN 4.3 Graft survival among intestinal transplant recipients transplanted in 2007, by age: deceased donors

Graft survival estimated using unadjusted Kaplan-Meier methods.



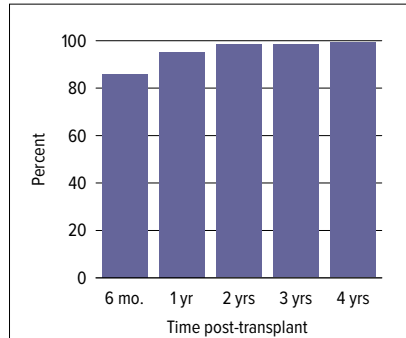
IN 4.4 Recipients alive & with a functioning intestinal transplant on June 30 of the year

Transplants before June 30 of the year that are still functioning. Patients are assumed alive with function unless a death or graft failure is recorded. A recipient can experience a graft failure and drop from the cohort, then be retransplanted and re-enter the cohort. Age cut is based on age at transplant.



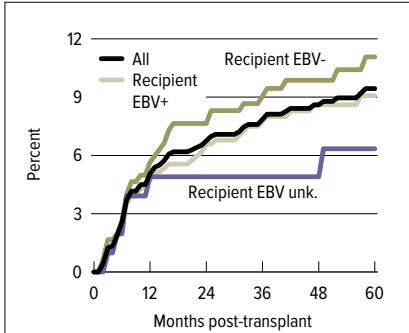
IN 4.5 Incidence of first acute rejection among patients receiving an intestinal transplant in 2006–2010

Acute rejection defined as a record of acute or hyperacute rejection, or a record of an anti-rejection drug being administered on either the Transplant Recipient Registration form or the Transplant Recipient Follow-up form. Only the first rejection event is counted. Cumulative incidence, defined as the probability of acute rejection at any time prior to the given time, is estimated using Kaplan-Meier competing risk methods.



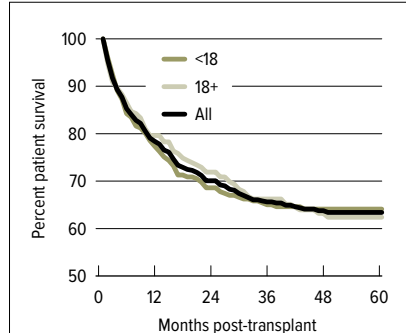
IN 4.6 Reported cumulative rehospitalizations among patients receiving an intestinal transplant in 2007–2012

Cumulative rate of rehospitalization; hospitalization identified from follow-up form. Patients required to be alive with graft function at each time period, so denominators reduce over time.



IN 4.7 Incidence of PTLD among patients receiving an intestinal transplant in 2006–2010, by recipient Epstein-Barr virus (EBV) status at transplant

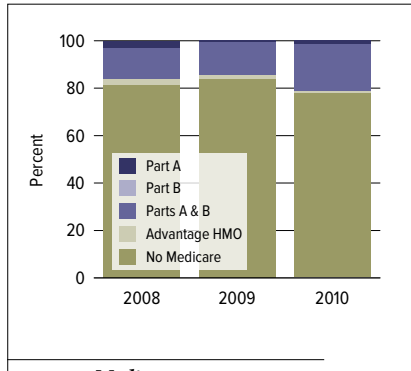
The cumulative incidence is estimated using Kaplan-Meier competing risks methods. PTLD is identified as either a reported complication or cause of death on the Transplant Recipient Follow-up form or on the Post-transplant Malignancy form as polymorphic PTLD, monomorphic PTLD, or Hodgkin's Disease. Only the earliest date of PTLD diagnosis is considered.



IN 4.8 Patient survival among intestinal transplant recipients, 2005–2007, by age: deceased donors

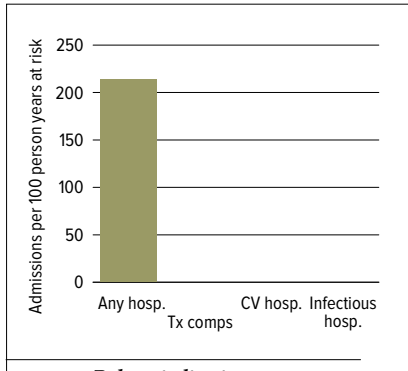
Percent patient survival using unadjusted Kaplan-Meier methods. For patients with more than one transplant during the period, only their first transplant is considered.

Medicare data



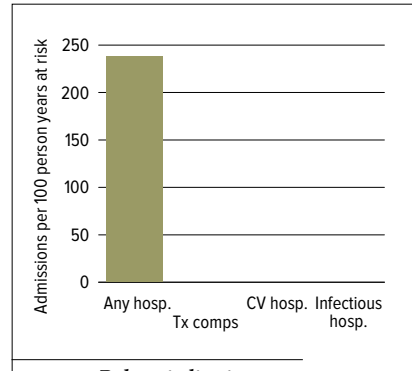
IN 5.1 Medicare coverage among intestinal transplant recipients

Coverage at the time of transplant as identified by the Medicare Beneficiary Annual Summary supplied by CMS.



IN 5.2 Rephospitalization rates among intestinal transplant recipients in the first post-transplant year

Transplant recipients, 2008, with Medicare as the primary payer at transplant. Rephospitalizations and reasons for rehospitalization determined from Medicare claims. First year rates are based on rehospitalizations occurring from initial discharge to one year later.



IN 5.3 Rephospitalization rates among intestinal transplant recipients in the second post-transplant year

Transplant recipients, 2008, with Medicare as the primary payer at transplant. Rephospitalizations and reasons for rehospitalization determined from Medicare claims. Second year rates are based on hospitalizations occurring from initial discharge+1 year to initial discharge+2 years.

Year 1 Cause of hospitalization	Percent of hospitalizations	Year 2 Cause of hospitalization	Percent of hospitalizations
Other	28.9	Genito-urinary and breast	*
Transplant complication	26.7	Respiratory infection	*
Other infection	*	Electrolyte, acid-base & vol. depletion	*
Respiratory infection	*	Gastro-intestinal	*
Gastro-intestinal	*	Other	*
Hypertensive heart & renal disease w/o CHF	*	Urinary tract infection	*
Electrolyte, acid-base & volume depletion	*	Transplant complication	*
Immune and hematologic	*	Hypertensive heart & renal disease w/o CHF	*
Bacteremia, viremia and septicemia	*	Respiratory	*
Respiratory	*		

IN 5.4 Top ten causes of rehospitalization among intestinal transplant recipients transplanted in 2008 with Medicare primary coverage

Transplant recipients, 2008, with Medicare as the primary payer at transplant. Reasons for rehospitalization determined from Medicare claims, denominator for percentages includes only those re-hospitalized. Values for cells with 9 or fewer patients are suppressed.

	# patients	Total costs		PPPY costs	
		Part A	Part B	Part A	Part B
All patients	24	5,645,764	768,237	292,963	39,864

IN 5.5 Total and per-person per-year (PPPY) Medicare costs (\$) among intestinal transplant recipients in the first post-transplant year

Costs among recipients transplanted in 2008 and 2009 who had Medicare as the primary payer at the time of transplant. First year costs include the transplant hospitalization. Costs incurred after a transplant failure are excluded. Values for cells with 9 or fewer patients are suppressed. Costs in the second post-transplant year are not shown due to insufficient patient counts.

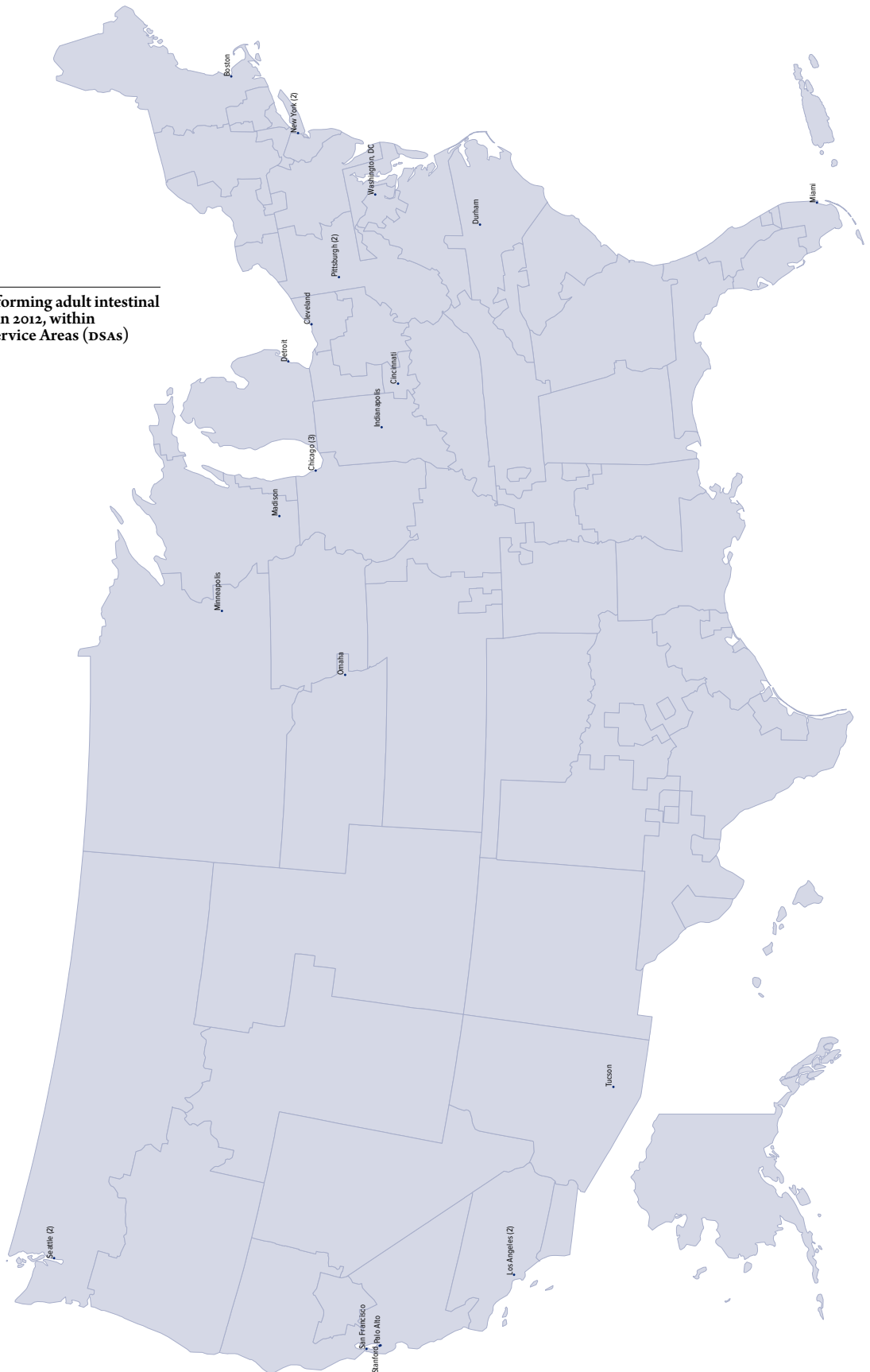
Medicare data

Total costs		2008 total costs			2009 total costs			2010 total costs		
		# patients	Part A	Part B	# patients	Part A	Part B	# patients	Part A	Part B
All patients		189	9,507,663	1,756,216	200	8,159,269	1,945,800	217	11,335,882	2,655,498
Age	0-11	*	*	*	*	*	*	*	*	*
	12-17	*	*	*	*	*	*	*	*	*
	18-34	56	2,589,729	483,994	59	2,506,970	675,234	61	2,641,061	831,997
	35-49	70	2,553,095	489,399	77	2,188,642	573,875	85	3,687,220	1,004,537
	50-64	47	2,759,115	557,459	51	2,793,397	526,127	56	4,063,672	589,529
	65+	*	*	*	*	*	*	*	*	*
Sex	Male	85	4,855,016	704,795	82	3,458,542	730,380	92	4,825,299	972,760
	Female	104	4,652,647	1,051,421	118	4,700,728	1,215,420	125	6,510,583	1,682,739
Race	White	163	8,286,315	1,488,216	177	7,324,922	1,672,931	182	10,043,215	2,228,540
	Black	14	625,887	159,662	14	366,025	184,039	22	753,267	310,023
	Hispanic	10	593,652	102,281	*	*	*	*	*	*
	Asian/Pacific Islander	*	*	*	*	*	*	*	*	*
	Other/unk.	*	*	*	*	†	*	*	*	*
Primary cause of disease	Necrotiz. enterocolitis	2	242,029	6,568	1	23,782	3,146	1	11,283	1,918
	Congenital SGS	3	200,987	31,346	2	32,430	40,300	3	184,833	43,623
	Other SGS	125	6,130,260	1,090,498	147	5,814,896	1,295,245	155	7,251,454	1,647,058
	Pseudo-obstruction	19	726,083	179,769	17	837,496	234,147	21	1,378,043	408,396
	Enteropathies	1	0	59,840	1	6,259	2,900	1	6,722	2,246
	Other/unk.	39	2,208,304	388,196	32	1,444,405	370,062	36	2,503,546	552,258
Per person per year costs		2008 PPPY costs			2009 PPPY costs			2010 PPPY costs		
All patients		189	58,697	10,842	200	47,303	11,281	217	59,533	13,946
Age	0-11	*	*	*	*	*	*	*	*	*
	12-17	*	*	*	*	*	*	*	*	*
	18-34	56	49,216	9,198	59	47,338	12,750	61	46,793	14,741
	35-49	70	41,877	8,027	77	31,854	8,352	85	48,863	13,312
	50-64	47	76,236	15,403	51	72,168	13,593	56	87,745	12,729
	65+	*	*	*	*	*	*	*	*	*
Sex	Male	85	70,567	10,244	82	48,895	10,326	92	62,417	12,583
	Female	104	49,933	11,284	118	46,196	11,944	125	57,561	14,877
Race	White	163	59,623	10,708	177	48,520	11,081	182	62,151	13,791
	Black	14	52,217	13,320	14	27,666	13,911	22	37,622	15,484
	Hispanic	10	65,861	11,347	*	*	*	*	*	*
	Asian/Pacific Islander	*	*	*	*	*	*	*	*	*
	Other/unk.	*	*	*	*	*	*	*	*	*
Primary cause of disease	Necrotiz. enterocolitis	2	121,014	3,284	1	23,848	3,154	1	11,314	1,924
	Congenital SGS	3	67,241	10,487	2	16,260	20,205	3	79,370	18,732
	Other SGS	125	57,875	10,295	147	46,646	10,390	155	53,803	12,221
	Pseudo-obstruction	19	38,420	9,512	17	51,987	14,535	21	71,958	21,325
	Enteropathies	1	0	157,134	1	6,277	2,908	1	6,740	2,252
	Other/unk.	39	69,473	12,213	32	52,085	13,344	36	77,843	17,171

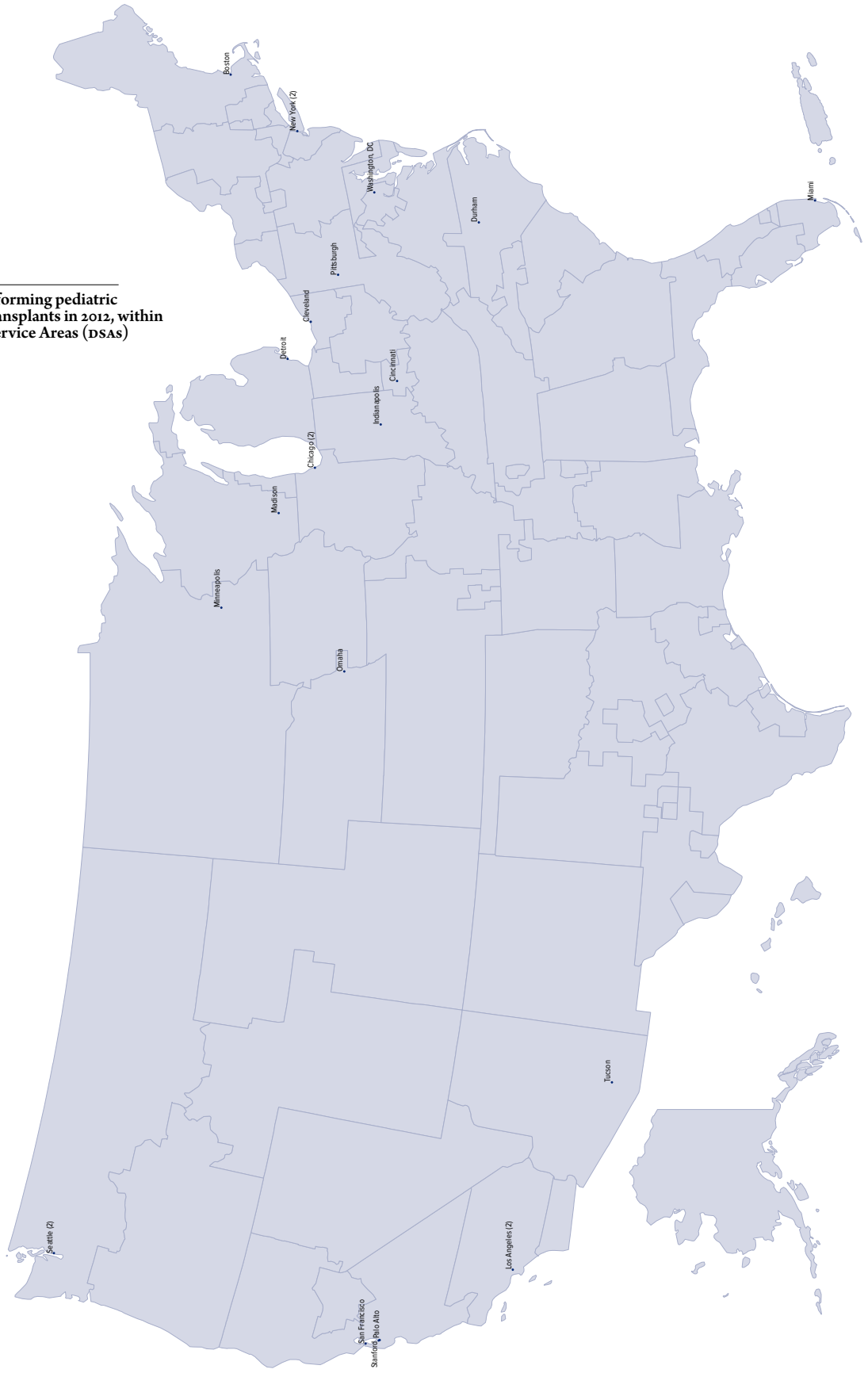
IN 5.6 Total calendar-year Medicare costs (\$) spent on intestinal transplant recipients, 2008, 2009, & 2010

Costs paid by Medicare in each calendar year among recipients alive with graft function in the given year, regardless of Medicare eligibility at the time of transplant. Costs incurred after transplant failure are excluded. Values for cells with 9 or fewer patients are suppressed.

IN 6.1 Centers performing adult intestinal transplants in 2012, within Donation Service Areas (DSAs)



IN 6.2 Centers performing pediatric intestinal transplants in 2012, within Donation Service Areas (DSAs)



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OPTN/SRTR 2012 Annual Data Report:

heart

ABSTRACT The number of heart transplants performed annually continues to increase gradually, and the number of adult candidates on the waiting list increased by 25% from 2004 to 2012. The heart transplant rate among active adult candidates peaked at 149 per 100 wait-list years in 2007 and has been declining since; in 2012, the rate was 93 heart transplants per 100 active wait-list years. Increased waiting times do not appear to be correlated with an overall increase in wait-list mortality. Since 2007, the proportion of patients on life support before transplant increased from 48.6% to 62.7% in 2012. Medical urgency categories have become less distinct, with most patients listed in higher urgency categories. Approximately 500 pediatric candidates are added to the waiting list each year; the number of transplants performed each year increased from 274 in 1998 to 372 in 2012. Graft survival in pediatric recipients continues to improve; 5-year graft survival for transplants performed in 2007 was 78.5%. Medicare paid for some or all of the care for nearly 40% of heart transplant recipients in 2010. Heart transplant appears to be more expensive than ventricular assist devices for managing end-stage heart failure, but is more effective and likely more cost-effective.

KEY WORDS End-stage heart failure, heart transplant, transplant outcomes, ventricular assist device.

The following message was handwritten by the young son of the recipient of my son's heart on November 8, 1994.
"Go heart donor, I would like to say thank you for donating a heart for my dad. I can't say thank you enough because he couldn't do hardly anything with his bad heart. My heart goes out to you for your lost loved one."

Bonnie, donor mother

Introduction

Heart transplant outcomes continue to improve due to sustained improvements in perioperative management, patient selection, and wait-list management. Mechanical circulatory support, particularly advances in implantable devices, has revolutionized the way end-stage heart failure patients are managed and has affected heart transplant trends in multiple ways.

The number of heart transplants performed annually continues to increase gradually. From 1998 to 2004, the number of heart transplants decreased by 14.2%. Since then, the number of heart transplants performed annually has increased by 17.1%; this increase may reflect, at least in part, the broader sharing policy begun in 2006. The most recent revision of the Organ Procurement and Transplantation Network (OPTN) heart allocation policy involved a temporary change in 1A status for patients with a total artificial heart. Although this policy has expired, OPTN heart allocation policies continue to be reviewed to address changing trends in heart failure management and outcomes. The current policy, based on three medical urgency statuses, does not stratify medical urgency with sufficient granularity. It is anticipated that future revisions of the policy will provide a greater degree of stratification to respond to the changing clinical profile of the advanced heart failure patient. A second challenge is wide regional variation in heart donation rates, waiting times, and, thereby, access to heart transplant. These variations are multifactorial and influenced not only by donor availability but also by center-specific practices. Nevertheless, identifying and seeking to understand these challenges to fair allocation practices will contribute to the development of better policies.

Adult Heart Transplant Waiting List Trends

NEW LISTINGS, TIME TO TRANSPLANT, AND WAIT-LIST MORTALITY

From 1998 to 2004, the number of listings for heart transplant declined. Since then, however, the number of new active adult (aged 18 years or older at listing) candidates on the waiting list has increased by 25% (Figure 1.1). From 2008 through 2012, 14,524 new candidates were added to the waiting list. The distribution of candidates waiting in the most urgent category

has shifted, with more status 1A and status 1B candidates and fewer status 2 and inactive candidates since 2006 (Figure 1.2). This shift may reflect the increase in ventricular assist device (VAD) implants and subsequent listing as status 1B. Also, recognizing that undergoing transplant as status 2 is unlikely, many centers are deferring listing candidates as status 2 until they qualify for a more urgent status, which may contribute to the decline in candidates listed as status 2.

The heart transplant rate among active candidates peaked at 149 per 100 wait-list years in 2007 and has been declining since; in 2012, the rate was 93 heart transplants per 100 active wait-list years (Figure 1.4). The rate appears to be increasing in women, as suggested by trends over the past 2 years, but this increase bears further observation. Of note, the 2012 transplant rate among status 2 candidates was 13 per 100 wait-list years, one-third the rate observed in 2007.

Among patients listed for transplant in 2009, 55.9% underwent transplant within 12 months of listing, 27.5% were still waiting at 12 months, and 8.7% had died. By 36 months, 66.7% had undergone transplant, 10.9% had died, and 13.9% were removed from the list for other reasons. Fewer than 10% were waiting by the end of the third year (Figure 1.7). Median time to transplant appeared to have reached a nadir for all medical urgency categories in 2006-2007 and has been gradually increasing since then. Median time to transplant is longest for status 2 candidates, at almost 20 months; median time to transplant for status 1A and status 1B candidates was 2.4 months and 6.9 months, respectively, in 2012. Considering the past decade as a whole, the median waiting time for status 1A candidates has not changed appreciably, although it has increased for status 1B and status 2 candidates. The median time to transplant among candidates with VADs at listing also reached a nadir of 3 months in 2006-2007 and has increased since then; in 2012, the median waiting time for candidates with VADs at listing was 8.7 months, the same as for candidates without VADs (Figure 1.8).

Pretransplant mortality rates include candidates who died while on the waiting list as well as those removed for being too ill, who subsequently died. In general, pretransplant mortality declined from 15.8 deaths per 100 wait-list years in 2002 to 12.4 in 2012 (Figure 1.10). There have been some notable trends among

subgroups. Although pretransplant mortality has typically been lowest for candidates aged 35 to 49 years, in 2012 it was lowest for candidates aged 50 to 64 years: 11.8 per 100 wait-list years. Pretransplant mortality was similar for all ethnic groups, ranging from 11 to 15 deaths per 100 wait-list years (Figure 1.10). Among candidates with coronary artery disease and cardiomyopathy, pretransplant mortality has declined, while it has fluctuated over time among candidates with congenital heart disease and valvular heart disease. Among candidates with VADs at time of listing, pretransplant mortality has declined substantially, from 95.7 per 100 wait-list years in 2002 and 44.7 per 100 wait-list years in 2007 to 13.25 per 100 wait-list years in 2012. Before 2010, pretransplant mortality among candidates with VADs was substantially higher than among candidates without VADs, but since 2010, pretransplant mortality has been essentially the same for candidates with and those without VADs at listing. As expected, the mortality rate was highest for candidates listed as status 1A. Pretransplant mortality among candidates listed as status 1A has declined dramatically over the past decade, from 141.8 per 100 wait-list years to 40.23. Similarly, wait-list mortality for candidates listed as status 1B declined from 33.9 per 100 wait-list years to 11.72 in 2012, and mortality for those listed as status 2 declined from 11.8 per 100 wait-list years to 7.66. The pretransplant mortality rate among inactive candidates has typically been relatively low; however, since 2002, the rate has increased from 8.6 per 100 wait-list years to 12.7 (Figure 1.10). Both favorable and unfavorable changes in condition, as well as other factors, may contribute to candidates being listed as inactive.

The waiting list continues to grow because more candidates are typically added than removed in a given year. In 2012, 3007 new candidates were added to the waiting list, while 2784 were removed; 2008 of those were removed due to undergoing transplant (Figure 1.6). The number of candidates removed from the list due to undergoing transplant remained steady from 2010 to 2012. The number removed from the list due to death remains substantial, 372 patients in 2012; 117 were removed for being too ill to undergo transplant, and 142 because their condition improved. Thus, we are still faced with a major imbalance in supply and demand that is associated with substantial mortality on the list (Figure 1.6).

CANDIDATE CHARACTERISTICS

In general, the age distribution of heart transplant candidates has been stable over the past decade. The percentage of candidates aged 18 to 34 years peaked at 11.0% in 2004 and declined to 9.8% in 2012. The proportions of candidates aged 35 to 49 years and 50 to 64 years similarly declined. On the other hand, the proportion of candidates aged 65 years or older continues to increase, from 12.8% in 2002 to 19.8% in 2012. There has been an increase in candidates from ethnic minority groups, with a notable increase in black candidates from 14.6% to 21.2% since 2002. The prevalence of cardiomyopathy as a cause for transplant increased to 51.5% compared with coronary artery disease, which declined to 37.1% (Figure 1.2).

The trend in VADs at listing persists with a substantial increase, particularly over the past 5 years. In 2012, 22.6% of candidates had a VAD at listing compared with 9.7% in 2007 (Figure 1.2).

The proportion of candidates awaiting heart transplant for an extended period is decreasing. In 2012, only 9.2% of candidates spent 4 or more years on the waiting list, compared with 18.7% in 2002 (Figure 1.2). The proportion of candidates waiting less than 1 year has stabilized at approximately 50% since 2007. Because time to transplant has increased in recent years, other factors, such as listing practices, may be contributing to the decrease in candidates waiting for an extended period.

DONATION

Heart donation rates remain flat; in 2012, there were 3.5 donations per 1000 deaths. The highest rates were among donors aged 15 to 34 years, who provided 17.9 hearts per 1000 deaths (Figure 2.1). Over the past 5 years, heart donation rates increased by 11% to 14% for ages 15-34, 35-44, and 45-54 years (Figure 2.1). Hispanics have had the highest heart donation rate of all ethnic categories, 4.3 per 1000 patient deaths in 2011 (Figure 2.1). Very few recovered hearts are discarded. Over the past decade, discard rates ranged from 0.5% to 1.4% of all hearts recovered for transplant. In 2012, 1.1% of hearts were discarded, a total of 28 hearts.

The most common cause of death among heart donors is head trauma (53.4%). The prevalence of head trauma as a

cause of death has declined over the past decade from 61.7%, while the prevalence of anoxia is increasing (Figure 2.3). Anoxia is the second most common cause of death among heart donors, accounting for 24.7% of heart-donor deaths in 2012. The proportion of donors with cerebrovascular disease, previously the second most common cause of death among donors, has also declined, and in 2012 was 18.6% (Figure 2.3).

Adult Heart Transplant

TRENDS IN HEART TRANSPLANT

From 1998 to 2004, the number of heart transplants performed nationwide persistently declined. Since then, transplant volume has been increasing, with the greatest annual rise, 5.9%, seen in 2010. Between 2011 and 2012, heart transplants increased 2.5%, from 2349 to 2407 transplants. Since 2002, the number of heart transplants performed in the US increased 10.0%, from 2188 to 2407 in 2012 (Figure 3.1). Heart retransplants increased during the past decade. Although the trend has been flat for the past 5 years, there was a slight decrease from 4.0% in 2011 to 3.2% in 2012 (Figure 3.4).

MULTI-ORGAN TRANSPLANTS

Heart transplants as part of multi-organ transplants have increased, due to increases in heart-liver and heart-kidney transplants. The proportion of heart transplants that are heart-lung exceeds the proportion that are heart-liver. The proportion of heart-lung transplants performed has been static, while the proportions of heart-liver and heart-kidney transplants appear to be increasing (Figure 3.3). In 2012, 130 heart transplants were performed simultaneously with other organs; 29 were heart-lung transplants, 78 heart-kidney, 22 heart-liver, and 1 heart-liver-kidney. The number of simultaneous heart-lung transplants has been static; however, a relative peak of 42 in 2010 was the highest number performed in a year in the past decade. In 2012, the most common specified reason for heart-lung transplant was congenital heart disease (24%). Forty-four percent of heart-kidney transplants were performed in patients with idiopathic dilated cardiomyopathy, and 42% in patients with coronary artery disease. The most common diagnoses in candidates for heart-liver transplant

were congenital heart disease (27%) and amyloidosis (27%). A single heart-liver-kidney transplant was performed in 2012 for congenital heart disease.

RECIPIENT CHARACTERISTICS AND POSTTRANSPLANT TRENDS

Forty-two percent of heart transplant recipients are aged 50 to 64 years. The proportion of candidates aged 65 years old or older increased noticeably compared with the other age groups, for whom the trend has been static or downward. Since 2002, the proportion of recipients aged 65 years or older increased from 10.1% to 15.1%. The number of women who underwent transplant increased 22% over the past 5 years, while the number of men increased only 2%. Transplants performed in members of ethnic minority groups continue to increase gradually, although the increase was 45% for Asians over the past 5 years, compared with 10% for blacks and 4% for Hispanics.

In 2012, 54.0% percent of heart transplants were performed in patients with cardiomyopathy, 32.8% in patients with coronary artery disease (CAD), and 9.9% in patients with congenital heart disease. The proportions of recipients with CAD and valvular heart disease are decreasing; considering the 10-year trend, the number of transplants in candidates with CAD decreased 15%, the number in candidates with cardiomyopathy and congenital heart disease increased 34% and 24% respectively, and the number in candidates with valvular heart disease decreased 44% (Figure 3.2). The proportion of adult recipients who were status 1A at the time of transplant surged over the decade from 34.8% to 58.5%; the proportion who underwent transplant at status 2 fell from 26.9% to 5.0%, and the proportion at status 1B remained the same. In 2012, 41.3% of adult recipients had prior VAD compared with only 23.2% in 2002 (Figure 3.6). The proportion of adult recipients with Medicare as primary insurer increased. Most recipients over the decade have had private insurance, but the proportion with private insurance decreased from 2002 to 2012, and the proportion with Medicare increased (Figure 3.6).

TRENDS IN LIFE SUPPORT

The introduction of mechanical circulatory support dramatically changed the treatment of advanced heart failure and the practice of transplant. A paradigm shift occurred regarding what constitutes the best bridging mechanism to allow patients an adequate quality of life while awaiting transplant, ensure survival to transplant, and ensure adequate physical condition and tolerance of surgery. This shift has been reflected in the distribution of circulatory support before transplant. Since 2007, the proportion of patients on life support before transplant increased from 48.6% to 62.7% in 2012. This increase appears to be primarily due to an increase in use of left ventricular assist devices (LVAD) at the time of transplant. The proportion of recipients using an LVAD increased from 22.0% in 2007 to 35.6% in 2012; the proportion using inotropes declined from 43.4% of all recipients to 36.2%. Thus, the proportion of candidates with LVADs now approximates the proportion receiving inotropes, whereas in 2007, the proportion of recipients with prior inotropes exceeded the proportion with VADs by nearly 2 fold. The proportions of recipients using intra-aortic balloon pumps, right ventricular assist devices, or ventilators before transplant declined over the past 5 years, while the proportions using extracorporeal membrane oxygenation, inhaled nitric oxide, or prostaglandin E remained unchanged and low (Figure 3.5).

POSTTRANSPLANT MORTALITY

Overall, mortality after transplant declined over the past decade (Figure 5.2). One-year survival was 88% for patients who underwent transplant from 2005 to 2007; 3-year survival was 81%, and 5-year survival was 75%. Although early survival appears to be similar for all age categories, by the end of year 1, survival was lowest for recipients aged 18 to 34 years and appeared to decline more than for other age groups. By the end of year 3, survival was only 75% for recipients aged 18 to 34 years, compared with 80% for those aged 65 years or older and 82% for the other age groups. By the end of year 5, survival for recipients aged 18 to 34 years was only 67%, compared with approximately 75% for the other age groups. Similarly, 5-year survival was significantly worse for black compared with white

recipients. Five-year survival was 72% for women compared with 76% for men, and 72% for recipients with VADs compared with 76% for recipients without VADs (Figure 5.1). Both differences reached statistical significance, although these slight variations may be clinically acceptable. Investigation into the factors associated with the poorer outcomes would be helpful. Survival also appears to be similar for the three status categories; 5-year survival was 73% for status 1A recipients, 77% for status 1B recipients, and 75% for status 2 recipients (Figure 5.3). Median survival was 11.6 years, and 12.7 years if the recipient survived the first year. This trend has been flat for the past decade (Figure 5.4). Nevertheless, the prevalence of recipients alive with a functioning heart graft continues to increase; the number was 26,291 on June 30, 2012 (Figure 5.5). The most common causes of early mortality (during the first 3 months) after transplant are infection (1.4%), a combination of cardiovascular and cerebrovascular events (1.3%), and graft failure (1.1%). By the end of the first year, infection is the most common cause, occurring in 2.3% of recipients; this is superseded by cardiovascular/cerebrovascular events at 2 years (3.0%). Cardiovascular/cerebrovascular events remain the most common cause of mortality throughout the first 10 years after heart transplant, followed by graft failure and infection (Figure 5.9).

POSTTRANSPLANT MORBIDITY

Acute rejection remains common, occurring in 23% of heart transplant recipients by year 1 after transplant and in 45% by year 5 (Figure 5.6). The majority of heart transplant recipients, 61.1%, are hospitalized by year 4, and 36.3% during the first year (Figure 5.7). Posttransplant lymphoproliferative disorder (PTLD) is infrequent, but occurs most frequently among recipients who are Epstein-Barr virus (EBV) negative. Of note, 93% of EBV-negative recipients received a heart from EBV-positive donors (Figure 4.3).

The rate of hospital admissions for patients who underwent transplant in 2008 with Medicare as primary payer was 133.4 per 100 person-years at risk in the first year after transplant, declining to 61.9 in year 2 (Figures 7.2 and 7.3). The most common reasons for hospitalization after transplant were transplant complications followed by infection (Figure 7.4).

GEOGRAPHIC VARIATIONS

Geographic variations in access to organ transplant occur for a variety of reasons, including factors related to center-specific practices, the organ procurement organization (OPO), and demographics inherent to a particular region. Between 2009 and 2011, organ donation rates varied considerably between states from 0 to 1.61 per 1000 deaths. In most states, donation rates changed only minimally from 2006-2008 to 2009-2011 (Figure 2.2). In 2011, the proportion of candidates who underwent transplant within 1 year of wait-listing also varied widely among OPOs, between 22% and 100%. This variability was observed even between OPOs within the same state (Figure 1.9). Finally, heart transplant rates vary widely. In 2011 to 2012, heart transplant rates varied by OPOs from 0 per 100 patient-years on the waiting list to 661 (Figure 1.5). Although these variations are striking, determination of their impact on pre-transplant mortality and on posttransplant outcomes will be useful in assessing their true significance.

SUMMARY

The 2012 trends may be a reflection of prior allocation policy changes and of the impact of evolving management of heart failure. Waiting times continue to increase, but this trend did not appear to correlate with an overall increase in wait-list mortality. Medical urgency categories have become less distinct, with the majority of patients being listed in the higher urgency categories. Heart transplant among candidates listed as status 2 is becoming exceedingly rare. Geographic variations in waiting times, donation rates, and transplant rates persist, although the clinical impact has not yet been determined. It is anticipated that revisions to the allocation policy will better prioritize medical urgency as a first step in ensuring equitable access.

Pediatric Heart Transplant

PEDIATRIC WAITING LIST TRENDS

The number of new pediatric patients added to the heart transplant waiting list remains at approximately 500 per year with very few added as inactive status (Figure 6.1). At year end 2012, a total of just over 300 candidates were awaiting heart

transplant, with 61% listed as active. Approximately 50% of pediatric heart transplant candidates on the waiting list were aged 5 years or younger, with almost equal numbers aged younger than 1 year and 1-5 years (Figure 6.2). Almost 60% of heart transplant candidates were white, 18.9% were black, 18.3% were Hispanic, and less than 5% were Asian. In 2012, 8.3% of candidates (n = 89) on the heart transplant waiting list had undergone a previous heart transplant (Figure 6.3). Of all wait-listed candidates in 2012, 4.3% (26) of those aged less than 6 years, 15.7% (24) of those aged 6 to 10 years, and 12.6% (39) of those aged 11 to 17 years were awaiting retransplant (Figure 6.3). Almost 70% of patients newly listed in 2009 underwent transplant within 3 years, 13.9% died, 14.3% were removed from the list, and 4.5% were still waiting (Figure 6.5). The rate of deceased donor transplant among active pediatric wait-list candidates decreased from a peak of almost 300 per 100 patient-years on the waiting list to 192 in 2012 (Figure 6.6), due largely to a growing waiting list. Transplant rates varied by age, with the highest rates in candidates aged less than 1 year, 408 transplants per 100 patient-years on the waiting list. Pre-transplant mortality decreased dramatically for all age groups. The pretransplant mortality rate was highest for candidates aged younger than 1 year, at 53 deaths per 100 wait-list years in 2010-2012 (Figure 6.7).

PEDIATRIC TRANSPLANT

The number of pediatric heart transplants performed each year increased from 274 in 1998 to 372 in 2012 (Figure 6.8). In 2012, 7.1% of heart transplant recipients had a history of previous heart transplant (Figure 6.9). Less than 2% of pediatric heart transplants were part of a multi-organ transplant (Figure 6.10). Over the past decade, age and sex of pediatric heart transplant recipients changed little (Figure 6.11). Congenital defects remain the most common primary cause of disease, 43.3% of recipients in 2010-2012. The proportion of recipients with private insurance decreased and Medicaid coverage increased. The proportion of patients who underwent transplant as status 1A increased from 65.0% in 2000-2002 to 87.9% in 2010-2012. VAD use increased from only 7.2% of transplant candidates in 2000-2002 to 20.1% in 2010-2012. ABO

incompatible transplant occurred in less than 1% of recipients in the early era, compared with 3.4% in 2010-2012.

PTLD is a significant concern in pediatric transplant. Among pediatric heart transplant recipients from 2008 to 2012, 41.8% were EBV negative and 48.2% were positive. The highest risk for EBV infection and PTLT occurs for EBV-negative recipients of EBV-positive donor organs, 31.4% of pediatric recipients (Figure 6.12). Incidence of PTLT among EBV-negative recipients was 6.6% at 5 years after transplant, compared with 2.6% among EBV-positive recipients (Figure 6.14).

Among pediatric heart transplant recipients from 2008 to 2012, 56.1% were cytomegalovirus (CMV) negative and 40.0% were positive (Figure 6.13). The combination of a CMV-positive donor and CMV-negative recipient occurred in 29.2% of transplants.

PEDIATRIC IMMUNOSUPPRESSION AND OUTCOMES

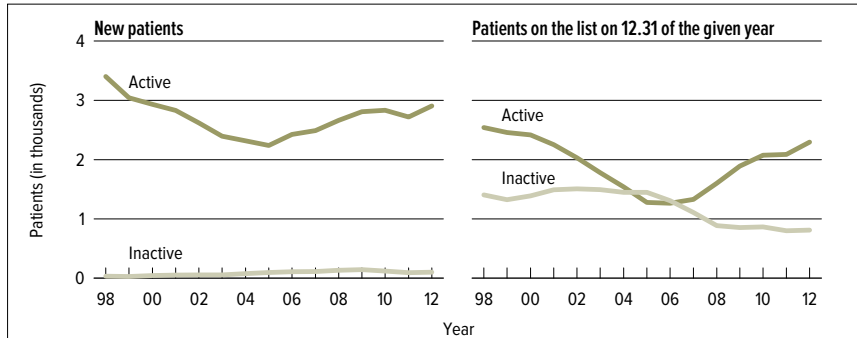
Substantial changes in maintenance immunosuppression have occurred in heart transplantation. Tacrolimus use increased from 25.2% in 1998 to 79.7% in 2012. Mycophenolate use increased from 32.8% in 1998 to 91.2% in 2012 (Figure 6.15). In 2011, mammalian target of rapamycin (mTOR) inhibitors were used in 1.6% of recipients at the time of transplant and in 9.8% at 1 year after transplant; steroids were used in 69.5% of recipients at the time of transplant and in 61.1% at 1 year. The most common induction therapy was T cell-depleting agents, used in almost half of heart transplant recipients in 2012. No induction therapy was used in 26.0% of recipients.

Graft survival after pediatric heart transplant has continued to improve. Graft survival for heart transplants in 2007 was 96.1% at 30 days, 89.5% at 1 year, 84.8% at 3 years, and 78.5% at 5 years (Figure 6.16). The rate of late graft failure is traditionally measured by the graft half-life conditional on 1-year survival, defined as the time to when half of grafts surviving at least 1 year are still functioning. For heart transplants performed in 2009-2010, the 1-year conditional graft half-life was 15.2 years (Figure 6.17). The incidence of first acute rejection increases over time after transplant with 22% of patients experiencing rejection in the first 12 months and 34% within 24 months after transplant (Figure 6.18).

Economics

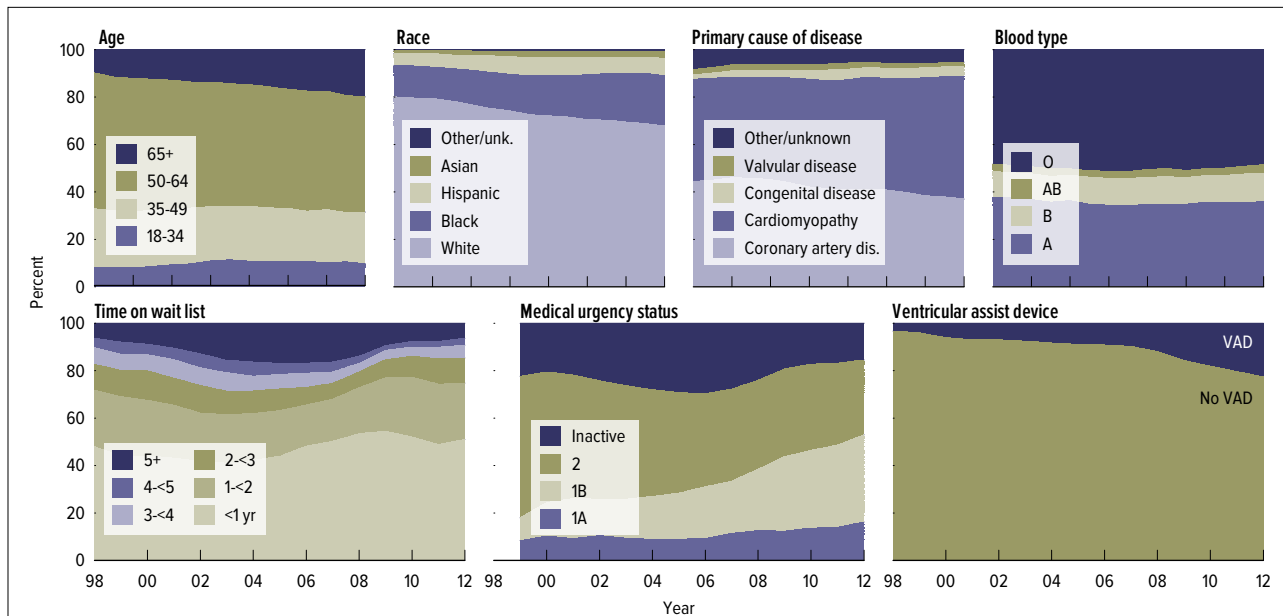
Medicare is the largest single payer for heart transplant in the United States, paying for some or all of the care for nearly 40% of recipients in 2010 (Figure 7.1). Average reimbursement for heart transplant recipients with primary Medicare coverage from transplant through 1 year after transplant was \$264,994 for Part A and \$33,634 for Part B (Figure 7.5), totaling \$298,628. This is approximately three to four times the Medicare Part A and B expenditure for a kidney transplant recipient (Kidney Chapter, Figure 8.5), and similar to the expenditure for lung or intestine transplant recipients (Lung Chapter, Figure 7.5; Intestine Chapter, Figure 5.5). Rehospitalization is common following heart transplant; rates are relatively high in the first year after transplant (Figure 7.2) and drop by half in the second year (Figure 7.3). Primary causes of rehospitalization are dominated by transplant complications and infections in both the first and second years after transplant (Figure 7.4). Rehospitalization rates and cause patterns are remarkably similar to those for kidney transplant (Kidney Chapter, Figures 8.2, 8.3, 8.4). Annual costs after the first year are dramatically smaller; Medicare Part A and B costs average \$23,671 and \$14,468, respectively, during year two (Figure 7.6), totaling \$38,139; cost is expected to remain stable in later years. Additional costs not accounted for here include reimbursement to hospitals for the transplant portion of the Medicare Cost Report and Medicare Part D. Including estimates for these brings average Medicare cost to approximately \$375,000 in the first year after transplant and approximately \$45,000 in subsequent years. Heart transplant appears to be somewhat more expensive than recent estimates of implantation of VADs for management of end-stage heart failure. However, heart transplant is considerably more effective than VADs and is likely a more cost-effective strategy. Heart transplant recipients account for 10% of all Medicare Part A and B expenditure following solid organ transplant, \$412 million or \$32,222 per patient in 2010 (Figure 7.7).

wait list



HR 1.1 Adult patients waiting for a heart transplant

Patients waiting for a transplant. A “new patient” is one who first joins the list during the given year, without having listed in a previous year. However, if a patient has previously been on the list, has been removed for a transplant, and has relisted since that transplant, the patient is considered a “new patient.” Patients concurrently listed at multiple centers are counted only once. Those with concurrent listings and active at any program are considered active; those inactive at all programs at which they are listed are considered inactive.



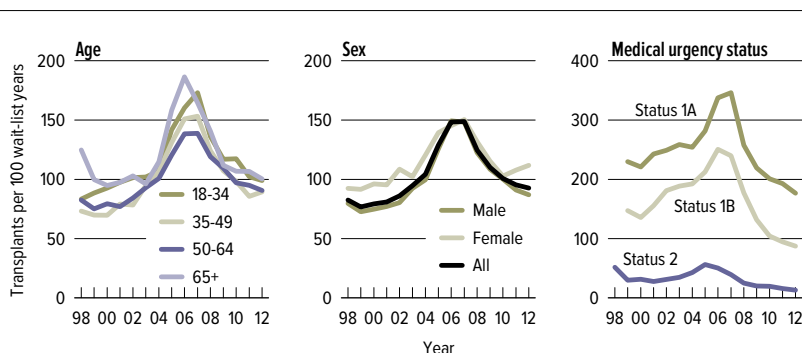
HR 1.2 Distribution of adult patients waiting for a heart transplant

Patients waiting for a transplant any time in the given year. Age determined on the earliest of listing date or December 31 of the given year. Concurrently listed patients are counted once. Ventricular assist device information comes from the OPTN Transplant Candidate Registration form at the time of listing, and includes LVAD, RVAD, TAH, and LVAD + RVAD. Medical urgency status is the earliest available per year for each patient. Medical urgency status is the most severe recorded in the given year.

	Level	2002		2012	
		N	%	N	%
Age	18-34	301	8.5	296	9.5
	35-49	863	24.3	687	22.1
	50-64	1,950	54.9	1,532	49.3
	65+	437	12.3	593	19.1
Sex	Female	808	22.8	767	24.7
	Male	2,743	77.2	2,341	75.3
Race	White	2,739	77.1	2,126	68.4
	Black	510	14.4	674	21.7
	Hispanic	219	6.2	220	7.1
	Asian	65	1.8	65	2.1
	Other/unknown	18	0.5	23	0.7
Primary cause of disease	Cor. artery disease	1,565	44.1	1,152	37.1
	Cardiomyopathy	1,565	44.1	1,589	51.5
	Congenital disease	116	3.3	150	4.8
	Valvular disease	77	2.2	62	2.0
	Other/unknown	228	6.4	155	5.0
Transplant history	Listed/first transplant	3,466	97.6	3,001	96.6
	Listed/subseq. transplant	85	2.4	107	3.4
Blood type	A	1,153	32.5	1,004	32.3
	B	342	9.6	325	10.5
	AB	58	1.6	58	1.9
	O	1,998	56.3	1,721	55.4
Time on wait list	<1 year	1,233	34.7	1,530	49.2
	1-<2	604	17.0	644	20.7
	2-<3	467	13.2	322	10.4
	3-<4	313	8.8	209	6.7
	4-<5	272	7.7	111	3.6
	5+	662	18.6	292	9.4
Medical urgency status	1A	84	2.5	269	8.9
	1B	315	9.3	1,078	35.5
	2	1,546	45.5	895	29.5
	Inactive	1,453	42.8	793	26.1
VAD status at listing	No VAD	3,432	96.6	2,435	78.3
	VAD	119	3.4	673	21.7
Multi-organ listing	Heart-Lung	140	3.9	33	1.1
	Heart-Kidney	53	1.5	126	4.1
	Heart-Pancreas	0	0.0	1	0.0
	Heart-Liver	5	0.1	32	1.0
	Heart alone	3,353	94.4	2,916	93.8
Total		3,551	100.0	3,108	100.0

HR 1.3 Characteristics of adult patients on the heart transplant waiting list on December 31, 2002 & December 31, 2012

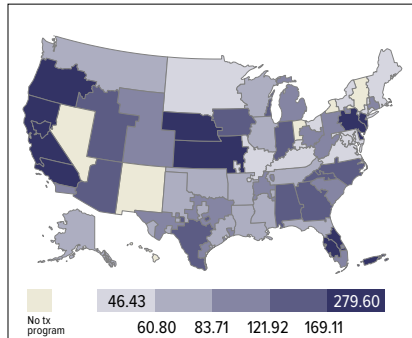
Patients waiting for a transplant on December 31, 2002 and December 31, 2012, regardless of first listing date; active/inactive status is on this date, and multiple listings are not counted.



HR 1.4 Heart transplant rates among active adult waiting list candidates, by age

Transplant rates are computed as the number of deceased donor transplants per 100 patient-years of active waiting time in a given year. Age is calculated on the first active listing date in a given year. Medical urgency status is the most severe recorded in the given year. Candidates with old Status 1 in 1998 and 1999 are excluded.

wait list



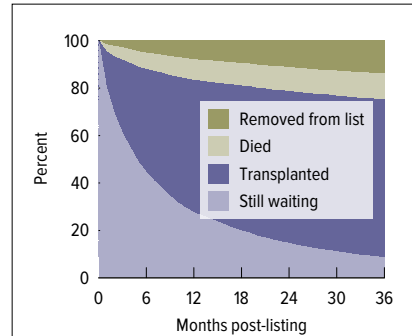
HR 1.5 Deceased donor heart transplant rates per 100 patient years on the waiting list among active adult candidates, by DSA, 2011–2012

Transplant rates by DSA of the listing center, limited to those with active time on the waiting list in 2011 and 2012; deceased donor transplants only. Maximum time per listing is two years. Patients with concurrent listings in a single DSA are counted once in that DSA, and those listed in multiple DSAs are counted separately per DSA.

	2010	2011	2012
Patients at start of year	2,737	2,932	2,883
Patients added during year	2,956	2,810	3,007
Patients removed during year	2,754	2,855	2,784
Patients at end of year	2,939	2,887	3,106
Removal reason			
Deceased donor transplant	1,993	1,948	2,008
Patient died	410	441	372
Patient refused transplant	12	16	20
Improved, tx not needed	157	164	142
Too sick to transplant	69	99	117
Other	113	187	125

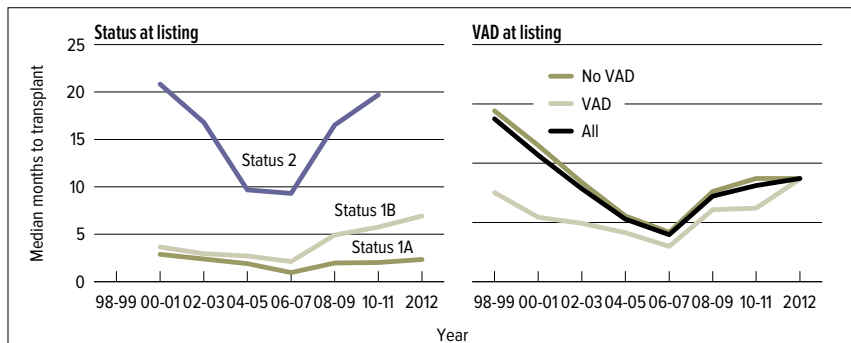
HR 1.6 Heart transplant waiting list activity among adult patients

Patients with concurrent listings at more than one center are counted once, from the time of earliest listing to the time of latest removal. Patients listed, transplanted, and re-listed are counted more than once. Patients are not considered “on the list” on the day they are removed. Thus, patient counts on January 1 may be different from patient counts on December 31 of the prior year. Patients listed for multi-organ transplants are included. Known deaths following removal for being too ill are counted as deaths.



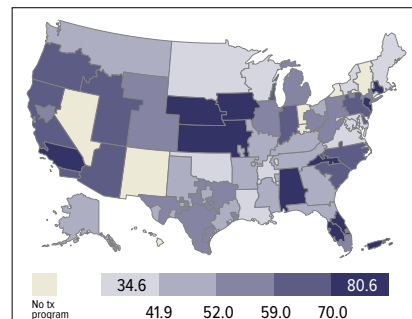
HR 1.7 Three-year outcomes for adult patients waiting for a heart transplant among new listings in 2009

Adult patients waiting for any heart transplant and first listed in 2009. Patients with concurrent listings at more than one center are counted once, from the time of the earliest listing to the time of latest removal.



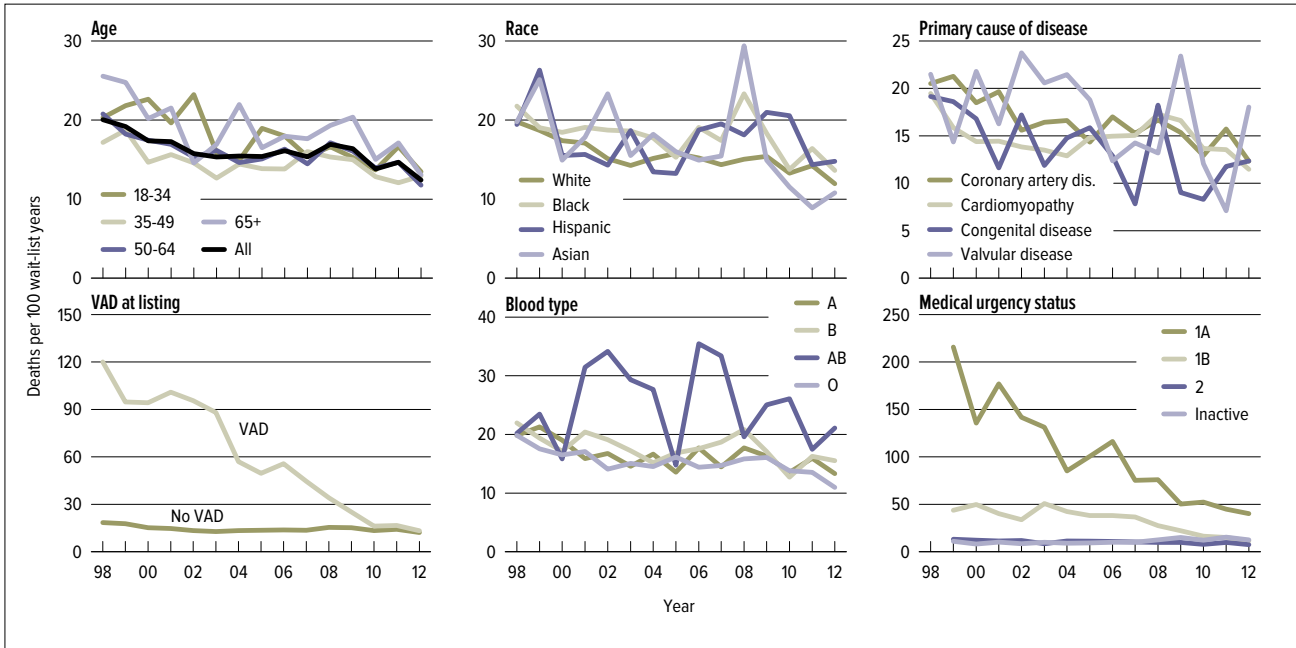
HR 1.8 Median months to heart transplant for wait-listed adult patients

Patients waiting for a transplant, with observations censored at December 31, 2012; Kaplan-Meier methods used to estimate time to transplant. If an estimate is not plotted, 50% of the cohort listed in that year had not been transplanted at the censoring date. Only the first transplant is counted.



HR 1.9 Percent of adult wait-listed patients, 2011, who received a deceased donor heart transplant within one year, by DSA

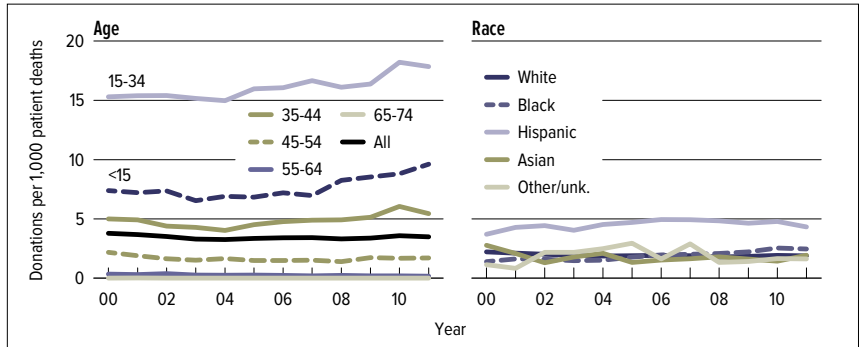
Patients with concurrent listings in a single DSA are counted once in that DSA, and those listed in multiple DSAs are counted separately per DSA.



HR 1.10 Pre-transplant mortality rates among adult patients wait-listed for a heart transplant

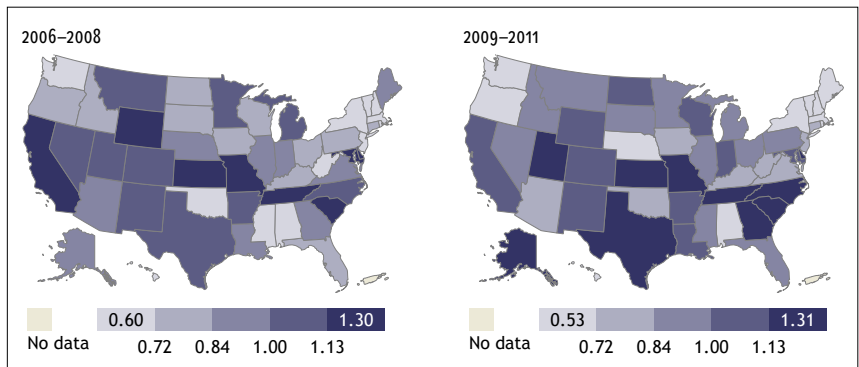
Patients waiting for a transplant. Mortality rates are computed as the number of deaths per 100 patient-years of waiting time in the given year. For rates shown by different characteristics, waiting time is calculated as the total waiting time in the year for patients in that group. Deaths occurring after removal are counted. Age is calculated on the latest of listing date or January 1st of the given year. Other patient characteristics come from the OPTN Transplant Candidate Registration form. Ventricular assist device information comes from the time of listing. Medical urgency status is the earliest known status in the given year.

deceased donation



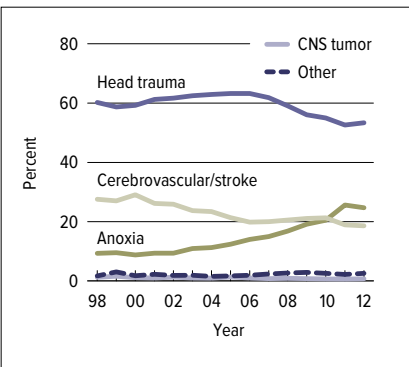
HR 2.1 Deceased donor heart donation rates

Numerator: Deceased donors age less than 75 whose heart was recovered for transplant. Denominator: us deaths per year, age less than 75. (Death data available at <http://www.cdc.gov/nchs/products/nvsr.htm>.) Death data were available only through 2011.



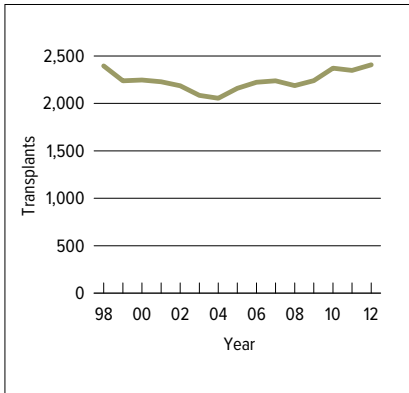
HR 2.2 Deceased donor heart donation rates (per 1,000 deaths), by state

Numerator: Deceased donors residing in the 50 states whose heart was recovered for transplant in the given year range. Denominator: us deaths by state during the given year range (death data available at <http://www.cdc.gov/nchs/products/nvsr.htm>). Rates are calculated within ranges of years for more stable estimates.



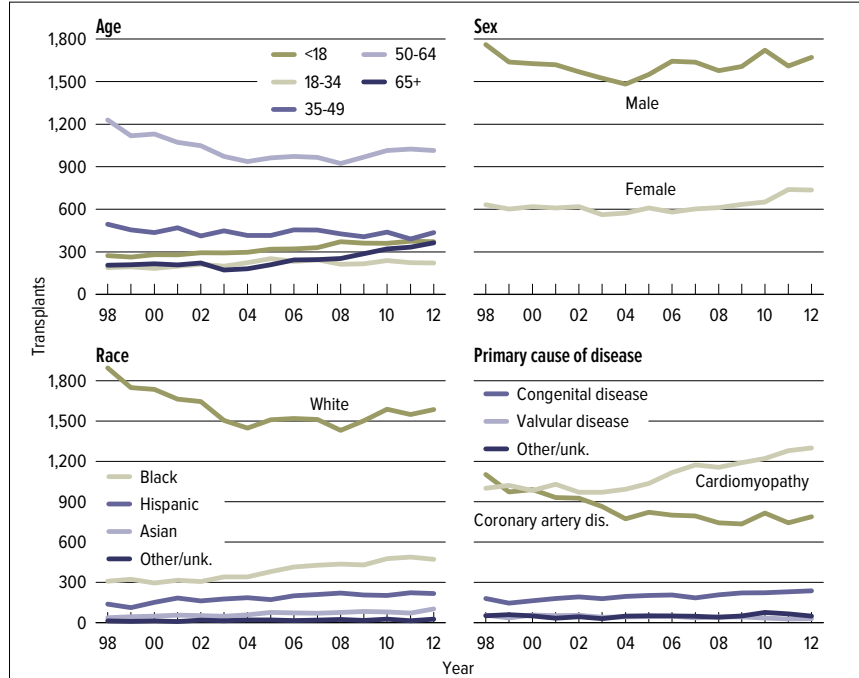
HR 2.3 Cause of death among deceased heart donors

Deceased donors whose heart was transplanted. CNS = central nervous system.



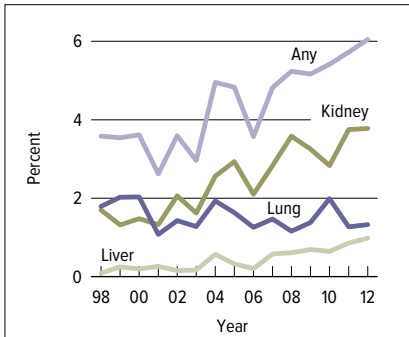
HR 3.1 Total heart transplants

Patients receiving a transplant, including multi-organ transplants and pediatric patients. Retransplants are counted.



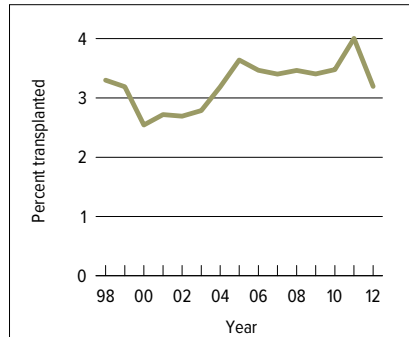
HR 3.2 Heart transplants

Patients receiving a transplant, including multi-organ transplants and pediatric patients. Retransplants are counted.



HR 3.3 Heart transplants that were part of a multi-organ transplant

All adult patients receiving a deceased donor heart transplant with at least one additional organ. A multi-organ transplant may include more than two different organs in total; if so, each non-heart organ will be considered separately. Kidney transplants include living donor transplants.



HR 3.4 Retransplants among adult heart transplant recipients

Patients receiving a heart retransplant in the given year.

	2007		2012	
	N	%	N	%
Any life support	929	48.6	1276	62.7
Intravenous Inotropes	829	43.4	736	36.2
Left ventricular assist device	421	22.0	724	35.6
Intra aortic balloon pump	136	7.1	120	5.9
Right ventricular assist device	88	4.6	53	2.6
Ventilator	49	2.6	20	1.0
Extra corporeal membrane oxygenation	15	0.8	18	0.9
Inhaled NO	7	0.4	5	0.2
Prostaglandins	1	0.1	1	0.0

HR 3.5 Adult heart recipients on circulatory support prior to transplant

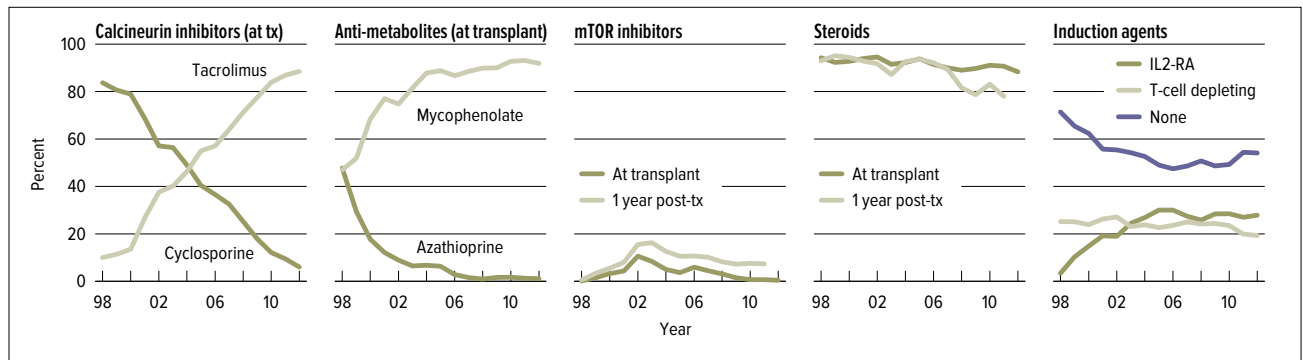
Patients may have more than one type of circulatory support.

transplant

		2002		2012				2002		2012		
	Level	N	%	N	%		Level	N	%	N	%	
Age	18-34	213	11.2	221	10.9	Primary payor	Private	1,120	59.1	1,020	50.1	
	35-49	412	21.8	436	21.4		Medicaid	216	11.4	250	12.3	
	50-64	1,048	55.3	1,015	49.9		Medicare	484	25.6	671	33.0	
	65+	221	11.7	363	17.8		Other government	57	3.0	48	2.4	
Sex	Female	480	25.3	563	27.7		Other/unknown	17	0.9	46	2.3	
	Male	1,414	74.7	1,472	72.3		Time on wait list	<30 days	470	24.8	591	29.0
Race	White	1,462	77.2	1,370	67.3			31-60 days	267	14.1	252	12.4
	Black	264	13.9	400	19.7			61-90 days	172	9.1	177	8.7
	Hispanic	115	6.1	160	7.9			3-<6 months	314	16.6	351	17.2
	Asian	39	2.1	87	4.3			6-<12 months	280	14.8	292	14.3
	Other/unlk.	14	0.7	18	0.9			1-<2 years	205	10.8	226	11.1
Primary cause of disease	Coronary artery dis.	924	48.8	784	38.5		2-<3 years	88	4.6	97	4.8	
	Cardiomyopathy	820	43.3	1,106	54.3	3+ years	98	5.2	49	2.4		
	Congenital disease	58	3.1	74	3.6	Medical urgency status	1A	660	34.8	1,190	58.5	
	Valvular disease	54	2.9	30	1.5		1B	723	38.2	743	36.5	
	Other/unknown	38	2.0	41	2.0	2	509	26.9	102	5.0		
Transplant history	First	1,843	97.3	1,970	96.8	VAD status	No VAD	1,454	76.8	1,194	58.7	
	Subsequent	51	2.7	65	3.2		VAD	440	23.2	841	41.3	
Blood type	A	840	44.4	858	42.2	Total		1,894	100.0	2,035	100.0	
	B	246	13.0	295	14.5							
	AB	76	4.0	128	6.3							
	O	732	38.6	754	37.1							

HR 3.6 Characteristics of adult heart transplant recipients, 2002 & 2012

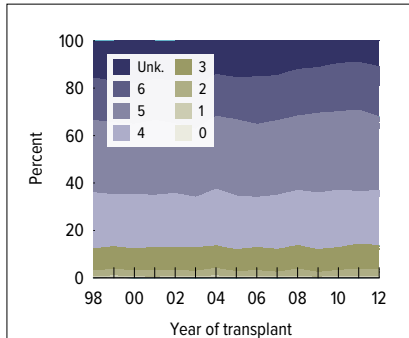
Patients receiving a transplant. Retransplants are counted. Ventricular assist device information comes from the OPTN Transplant Recipient Registration form and includes LVAD, RVAD, TAH, and LVAD + RVAD.



HR 3.7 Immunosuppression use in adult heart transplant recipients

One-year post-transplant data limited to patients alive with graft function one year post-transplant. Mycophenolate group includes mycophenolate mofetil and mycophenolate sodium.

donor-recipient matching



HR 4.1 Total HLA mismatches among adult heart transplant recipients

Donor and recipient antigen matching is based on the OPTN's antigen values and split equivalences policy as of 2012.

RECIPIENT	DONOR			Total
	Negative	Positive	Unknown	
Negative	14.2	23.1	0.1	37.4
Positive	21.8	36.1	0.1	58.0
Unknown	1.7	2.9	0.0	4.6
Total	37.7	62.1	0.2	100

HR 4.2 Adult heart donor-recipient cytomegalovirus (CMV) serology matching, 2008–2012

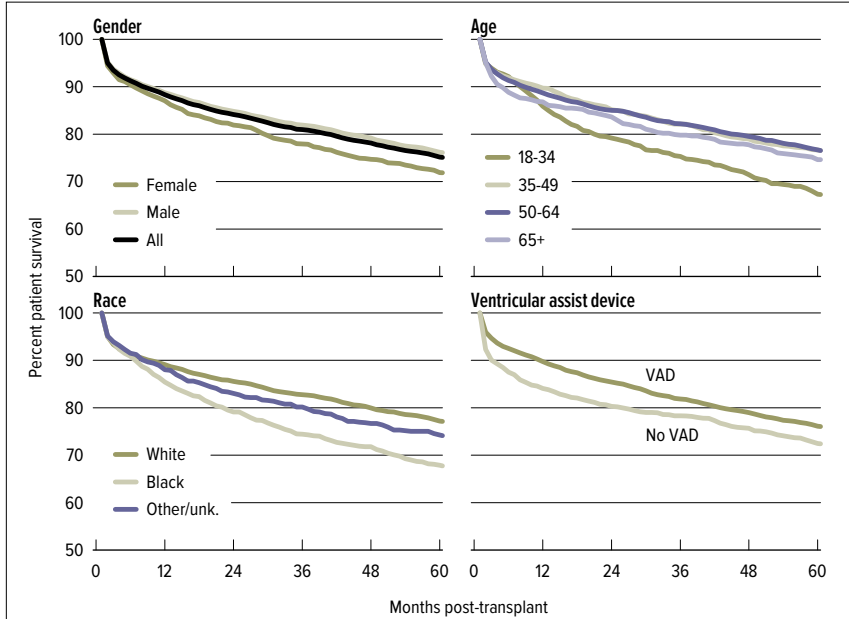
Adult transplant cohort from 2008–2012. Donor serology is reported on the OPTN donor registration forms; recipient serology is reported on the OPTN recipient registration forms. Any evidence for a positive serology is taken to indicate that the person is positive for the given serology; if all fields are unknown, not done, or pending, the person is considered to be “unknown” for that serology; otherwise, serology is assumed negative.

RECIPIENT	DONOR			Total
	Negative	Positive	Unknown	
Negative	0.8	12.4	0.0	13.3
Positive	3.8	65.4	0.3	69.4
Unknown	0.8	16.5	0.1	17.3
Total	5.4	94.2	0.4	100

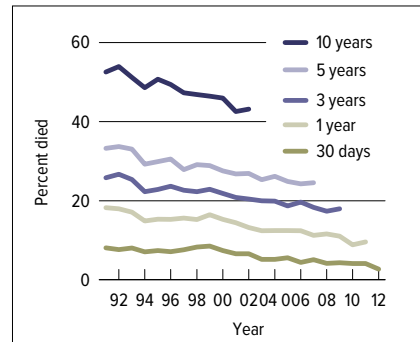
HR 4.3 Adult heart donor-recipient Epstein-Barr virus (EBV) serology matching, 2008–2012

Adult transplant cohort from 2008–2012. Donor serology is reported on the OPTN donor registration forms; recipient serology is reported on the OPTN recipient registration forms. Any evidence for a positive serology is taken to indicate that the person is positive for the given serology; if all fields are unknown, not done, or pending, the person is considered to be “unknown” for that serology; otherwise, serology is assumed negative.

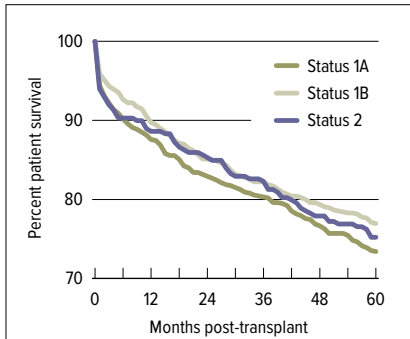
outcomes



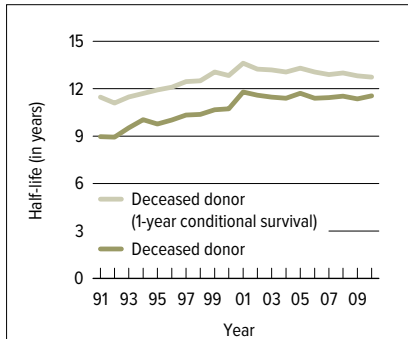
HR 5.1 Patient survival among adult heart transplant recipients, 2005–2007
 Percent patient survival using unadjusted Kaplan-Meier methods. For patients with more than one transplant during the period, only their first transplant is considered. VAD status for each patient comes from time of transplant.



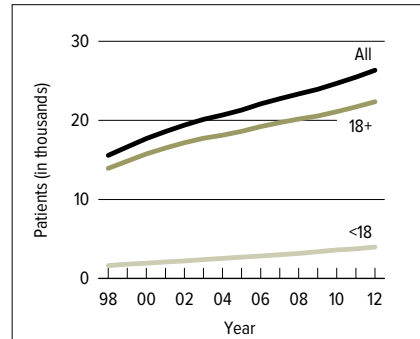
HR 5.2 Patient deaths among adult heart transplant recipients
 Cox proportional hazards models reporting probability, adjusting for age, sex, and race.



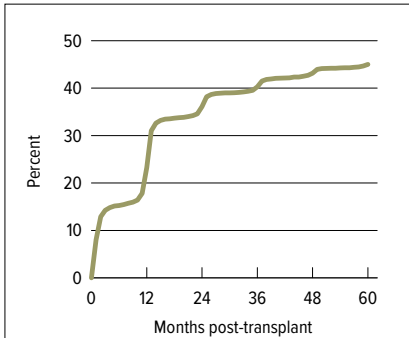
HR 5.3 Patient survival among adult heart transplant recipients transplanted in 2007
 Recipient survival estimated using unadjusted Kaplan-Meier methods.



HR 5.4 Half-lives for adult heart transplant recipients
 The half-life for a transplant cohort (e.g. 2009 heart transplants) is the time point in follow-up at which 50% of the transplanted grafts have failed. A conditional half-life for a transplant cohort is the same calculation but limited to those who survive with function at least 1 year post-transplant.

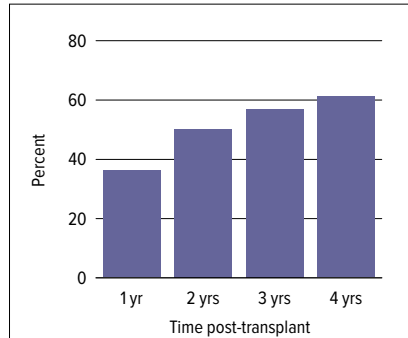


HR 5.5 Recipients alive & with a functioning heart transplant on June 30 of the year
 Transplants before June 30 of the year that are still functioning. Patients are assumed alive with function unless a death or graft failure is recorded. A recipient can experience a graft failure and drop from the cohort, then be retransplanted and re-enter the cohort. Age cut is based on age at transplant.



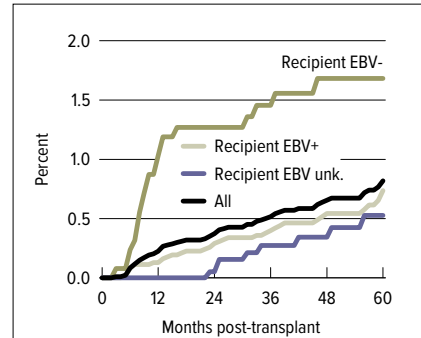
HR 5.6 Incidence of first acute rejection among adult patients receiving a heart transplant in 2006–2010

Acute rejection defined as a record of acute or hyperacute rejection, or a record of an anti-rejection drug being administered on either the Transplant Recipient Registration form or the Transplant Recipient Follow-up form. Only the first rejection event is counted. Cumulative incidence, defined as the probability of acute rejection at any time prior to the given time, is estimated using Kaplan-Meier competing risk methods.



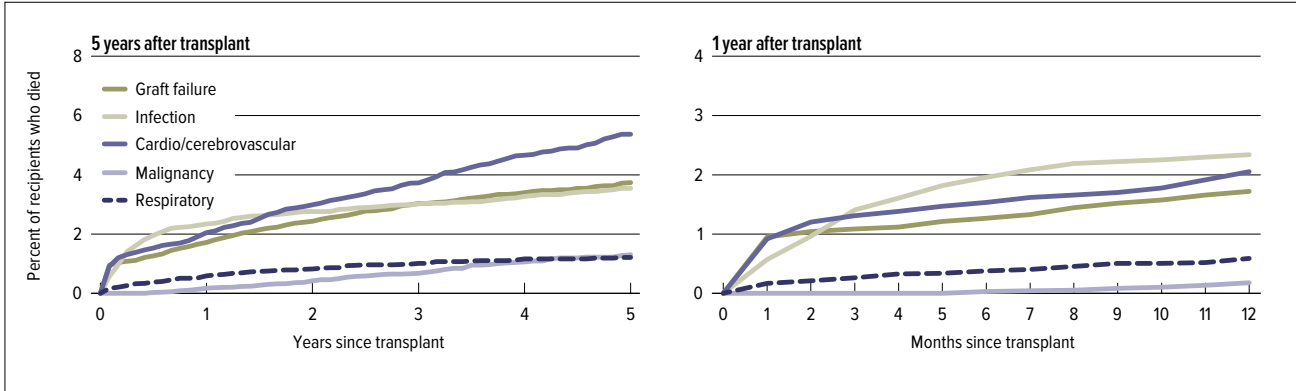
HR 5.7 Reported cumulative incidence of rehospitalizations among adult patients receiving a heart transplant in 2007–2012

Cumulative rate of rehospitalization; hospitalization identified from follow-up form. Patients required to be alive with graft function at each time period, so denominators reduce over time.



HR 5.8 Incidence of PTLD among adult patients receiving a heart transplant in 2006–2010, by recipient Epstein-Barr virus (EBV) status at transplant

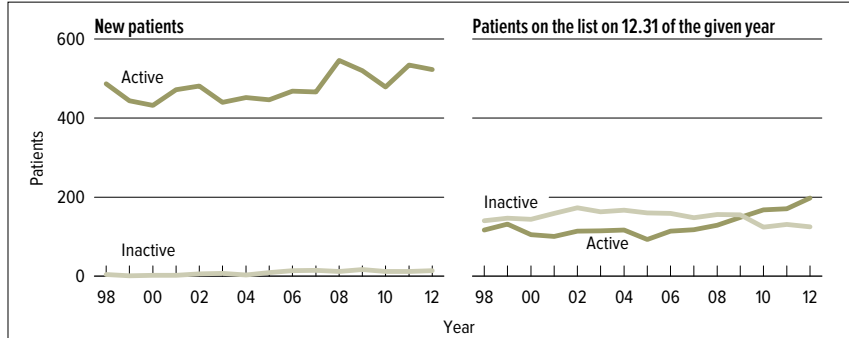
The cumulative incidence is estimated using Kaplan-Meier competing risks methods. PTLD is identified as either a reported complication or cause of death on the Transplant Recipient Follow-up form or on the Post-transplant Malignancy form as polymorphic PTLD, monomorphic PTLD, or Hodgkin's Disease. Only the earliest date of PTLD diagnosis is considered.



HR 5.9 Cumulative incidence of death by cause among adult heart recipients transplanted 2006–2010

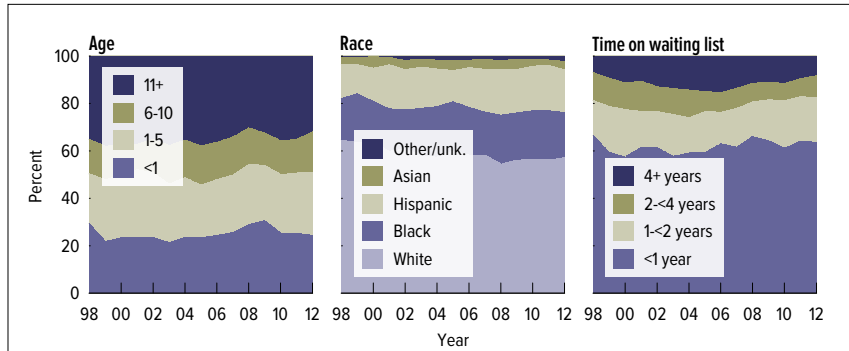
Primary cause of death is as reported by the OPTN from the Transplant Follow-up form. Other causes of death include hemorrhage, trauma, non-compliance, unspecified other, unknown, etc. Cumulative incidence is estimated using Kaplan-Meier competing risk methods.

pediatric transplant



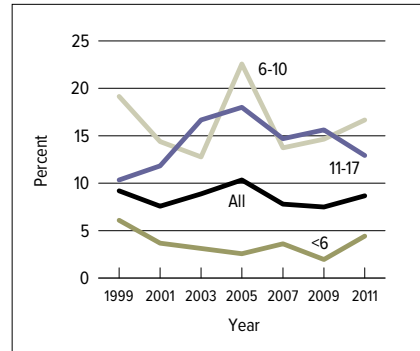
HR 6.1 Pediatric patients waiting for a heart transplant

Patients waiting for a transplant. A "new patient" is one who first joins the list during the given year, without having listed in a previous year. However, if a patient has previously been on the list, has been removed for a transplant, and has listed since that transplant, the patient is considered a "new patient." Patients concurrently listed at multiple centers are counted only once. Those with concurrent listings and active at any program are considered active; those inactive at all programs at which they are listed are considered inactive.



HR 6.2 Distribution of pediatric patients waiting for a heart transplant

Patients waiting for a transplant any time in the given year. Age determined on the latest of listing date or January 1 of the given year. Concurrently listed patients are counted once.



HR 6.3 Prior heart transplant in pediatric patients waiting for a heart transplant, by age

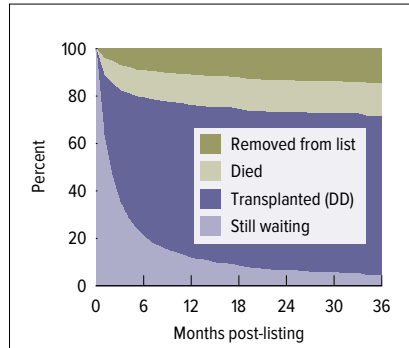
Prior transplant is obtained from the OPTN Transplant Candidate Registration form.

pediatric transplant

	2010	2011	2012
Patients at start of year	317	304	307
Patients added during year	491	546	537
Pts removed during year	503	542	514
Patients at end of year	305	308	330
Removal reason			
Received a transplant	366	386	380
Patient died	68	70	67
Patient refused transplant	2	0	0
Improved, tx not needed	43	48	44
Too sick to transplant	21	24	18
Other	3	14	5

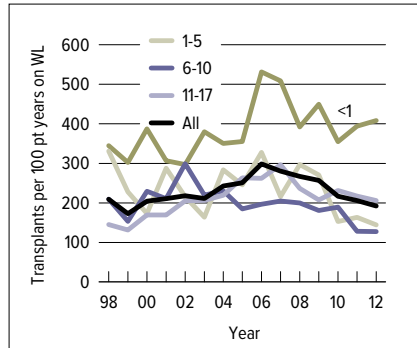
HR 6.4 Heart transplant waiting list activity among pediatric patients

Patients with concurrent listings at more than one center are counted once, from the time of earliest listing to the time of latest removal. Patients listed, transplanted, and re-listed are counted more than once. Patients are not considered "on the list" on the day they are removed. Thus, patient counts on January 1 may be different from patient counts on December 31 of the prior year. Patients listed for multi-organ transplants are included.



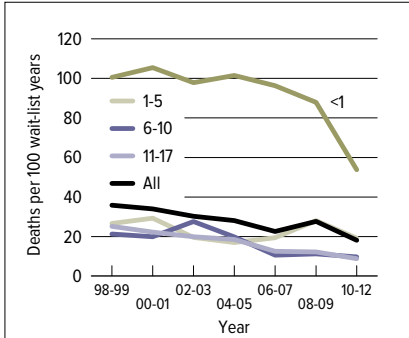
HR 6.5 Three-year outcomes for pediatric patients waiting for a heart transplant among new listings in 2009

Patients waiting for a transplant and first listed in 2009. Patients with concurrent listings at more than one center are counted once, from the time of the earliest listing to the time of latest removal.



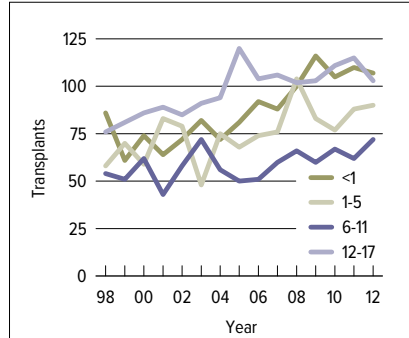
HR 6.6 Heart transplant rates among active pediatric waiting list candidates, by age

Transplant rates are computed as the number of deceased donor transplants per 100 patient-years of active waiting time in the given year. Age is calculated on the first active listing date in a given year.



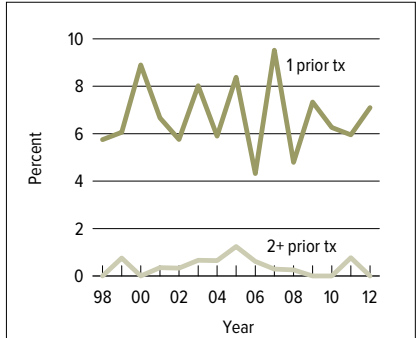
HR 6.7 Pre-transplant mortality rates among pediatric patients wait-listed for a heart transplant, by age

Patients waiting for a transplant. Mortality rates are computed as the number of deaths per 100 patient-years of waiting time in the given interval. Waiting time is calculated as the total waiting time per age group in the interval. Only deaths that occur prior to removal from the waiting list are counted. Age is calculated on the latest of listing date or January 1 of the given period.



HR 6.8 Pediatric heart transplants, by age

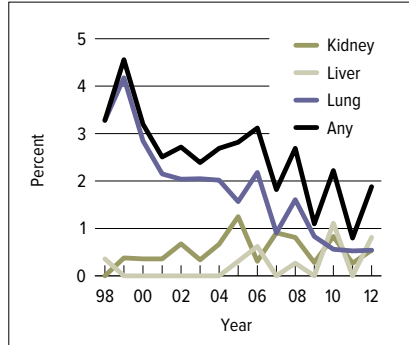
Patients receiving a heart or heart-lung transplant.



HR 6.9 Retransplants among pediatric heart transplant recipients

Includes patients transplanted after age 17, but listed at age 17 or younger. Retransplanted patients include only those with a prior transplant of the same type.

pediatric transplant



HR 6.10 Pediatric heart transplants that were part of a multi-organ transplant

Patients receiving a deceased donor heart transplant with at least one additional organ. A multi-organ transplant may include more than two different organs in total; if so, each non-heart organ will be considered separately.

RECIPIENT	DONOR			Total
	Negative	Positive	Unknown	
Negative	9.7	31.4	0.7	41.8
Positive	11.5	36.0	0.8	48.2
Unknown	2.5	7.2	0.3	10.0
Total	23.7	74.6	1.8	100

HR 6.12 Heart donor-recipient Epstein-Barr virus (EBV) serology matching for pediatric transplant recipients, 2008-2012

Pediatric transplant cohort from 2008-2012. Donor EBV serology is reported on the OPTN donor registration forms; recipient EBV serology is reported on the OPTN recipient registration forms. Any evidence for a positive serology is taken to indicate that the person is positive for EBV; if all fields are unknown, not done, or pending, the person is considered to be "unknown" for that serology; otherwise, serology is assumed negative.

RECIPIENT	DONOR			Total
	Negative	Positive	Unknown	
Negative	26.6	29.2	0.3	56.1
Positive	17.8	21.9	0.3	40.0
Unknown	1.6	2.2	0.1	3.9
Total	46.0	53.3	0.7	100

HR 6.13 Heart donor-recipient cytomegalovirus (CMV) serology matching for pediatric transplant recipients, 2008-2012

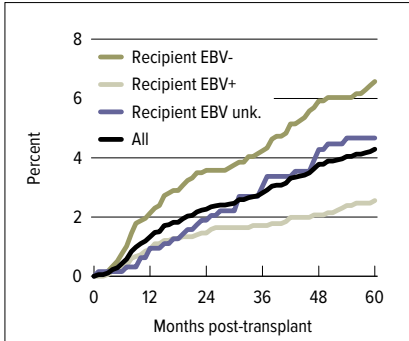
Pediatric transplant cohort from 2008-2012. Donor CMV serology is reported on the OPTN donor registration forms; recipient CMV serology is reported on the OPTN recipient registration forms. Any evidence for a positive serology is taken to indicate that the person is positive for CMV; if all fields are unknown, not done, or pending, the person is considered to be "unknown" for that serology; otherwise, serology is assumed negative.

Level	2000-2002		2010-2012		
	N	%	N	%	
Age	<1	208	24.9	322	29.2
	1-5	219	26.3	254	23.1
	6-10	115	13.8	157	14.3
	11-17	292	35.0	368	33.4
Sex	Female	385	46.2	508	46.1
	Male	449	53.8	593	53.9
Race	White	516	61.9	615	55.9
	Black	138	16.5	230	20.9
	Hispanic	134	16.1	187	17.0
	Asian	40	4.8	45	4.1
	Other/unk.	6	0.7	24	2.2
Primary cause of disease	Congenital defect	357	42.8	477	43.3
	Dilated myopathy: idiopathic	269	32.3	316	28.7
	Restrictive myopathy: idiopathic	50	6.0	49	4.5
	Dilated myopathy: myocarditis	20	2.4	49	4.5
	All others	138	16.5	210	19.1
Transplant history	First transplant	773	92.7	1,027	93.3
	Subsequent	61	7.3	74	6.7
Blood type	A	350	42.0	413	37.5
	B	98	11.8	146	13.3
	AB	30	3.6	54	4.9
	O	356	42.7	488	44.3
Primary payer	Private	465	55.8	521	47.3
	Medicaid	295	35.4	486	44.1
	Other public	42	5.0	69	6.3
	Other	32	3.8	25	2.3
Time on wait list	<30 days	388	46.5	400	36.3
	31-60 days	144	17.3	223	20.3
	61-90 days	94	11.3	135	12.3
	3-6 months	105	12.6	191	17.3
	6-12 months	61	7.3	104	9.4
	1-2 years	30	3.6	36	3.3
	2-3 years	9	1.1	5	0.5
3+ years	3	0.4	7	0.6	
Status	1A	542	65.0	968	87.9
	1B	126	15.1	78	7.1
	2	166	19.9	55	5.0
Patient on VAD	No	774	92.8	880	79.9
	Yes	60	7.2	221	20.1
PRA	0	553	66.3	590	53.6
	1-19	97	11.6	163	14.8
	20-79	52	6.2	165	15.0
	80-100	25	3.0	57	5.2
	Missing	107	12.8	126	11.4
ABO	Identical	651	78.1	863	78.4
	Compatible	177	21.2	201	18.3
	Incompatible	6	0.7	37	3.4
All patients		834	100.0	1,101	100.0

HR 6.11 Characteristics of pediatric heart transplant patients, 2000-2002 & 2010-2012

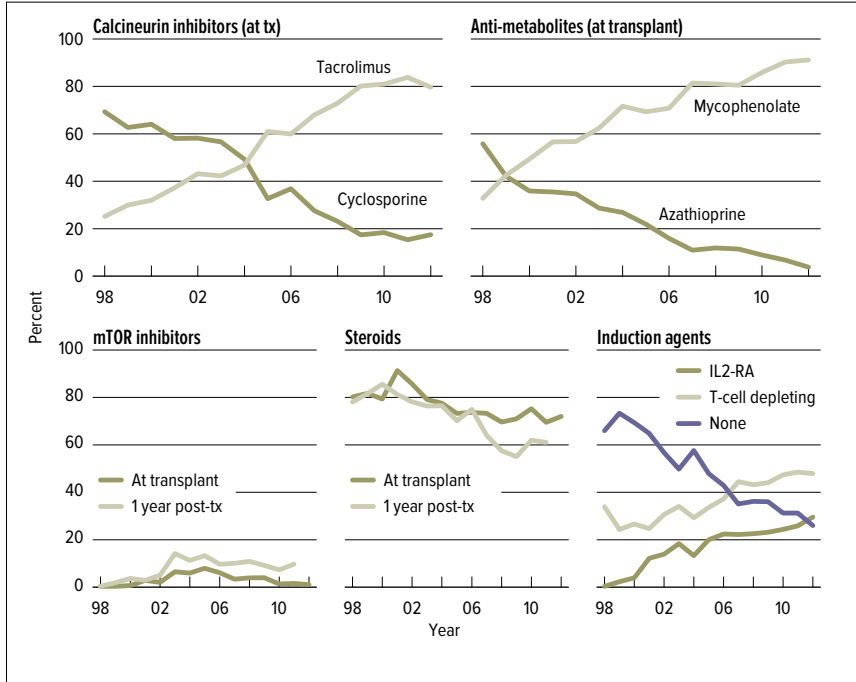
Patients receiving a transplant. Retransplants are counted.

pediatric transplant



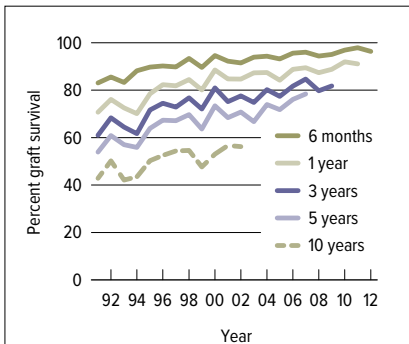
HR 6.14 Incidence of PTLD among pediatric patients receiving a heart transplant, 2000–2010, by recipient Epstein-Barr virus (EBV) status at transplant

The cumulative incidence is estimated using Kaplan-Meier competing risks methods. PTLD is identified as either a reported complication or cause of death on the Transplant Recipient Follow-up form or on the Post-transplant Malignancy form as polymorphic PTLD, monomorphic PTLD, or Hodgkin's Disease. Only the earliest date of PTLD diagnosis is considered.



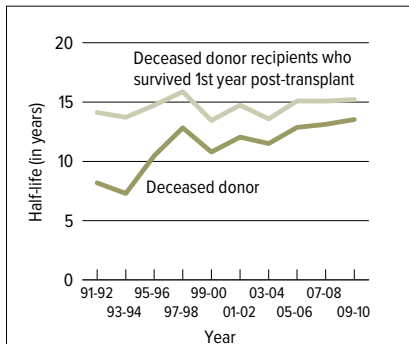
HR 6.15 Immunosuppression use among pediatric heart transplant recipients

One-year post-transplant data limited to patients alive with graft function one year post-transplant. Mycophenolate group includes mycophenolate mofetil and mycophenolate sodium.



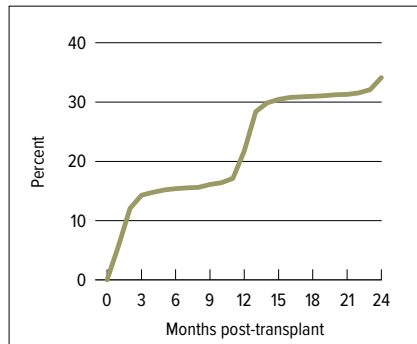
HR 6.16 Graft survival among pediatric heart transplant recipients

Estimates computed with Cox proportional hazards model, adjusted for age, sex, and race.



HR 6.17 Half-lives for pediatric heart transplant recipients

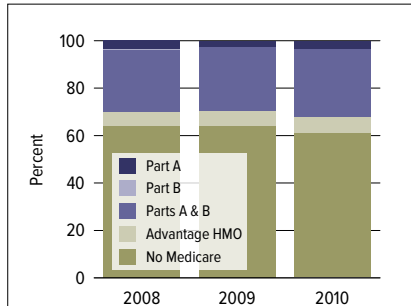
The half-life for a transplant cohort (e.g. 2009 heart transplants) is the time point at which 50% of the transplanted grafts have failed. A conditional half-life for a transplant cohort is the same calculation but limited to those who survive with function at least 1 year post-transplant.



HR 6.18 Incidence of first acute rejection among pediatric patients receiving a heart transplant in 2006–2011

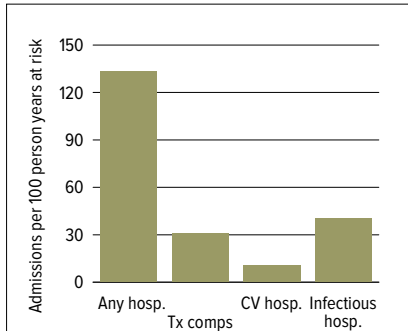
Acute rejection defined as a record of acute or hyperacute rejection, or a record of an anti-rejection drug being administered on either the Transplant Recipient Registration form or the Transplant Recipient Follow-up form. Only the first rejection event is counted. Cumulative incidence, defined as the probability of acute rejection at any time prior to the given time, is estimated using Kaplan-Meier competing risk methods.

Medicare data



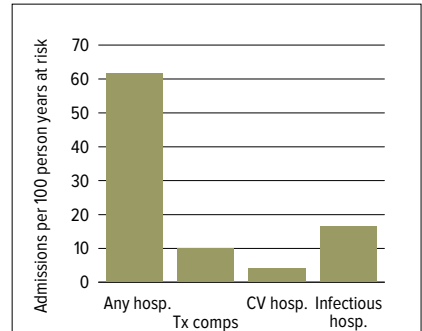
HR 7.1 Medicare coverage among heart transplant recipients

Coverage at the time of transplant as identified by the Medicare Beneficiary Annual Summary supplied by CMS.



HR 7.2 Rehospitalization rates among heart transplant recipients in the first post-transplant year

Transplant recipients, 2008, with Medicare as the primary payer at transplant. Rehospitalizations and reasons for rehospitalization determined from Medicare claims. First year rates are based on rehospitalizations occurring from initial discharge to one year later.



HR 7.3 Rehospitalization rates among heart transplant recipients in the second post-transplant year

Transplant recipients, 2008, with Medicare as the primary payer at transplant. Rehospitalizations and reasons for rehospitalization determined from Medicare claims. Second year rates are based on hospitalizations occurring from initial discharge+1 year to initial discharge+2 years.

Year 1 Cause of hospitalization	Percent of hospitalizations	Year 2 Cause of hospitalization	Percent of hospitalizations
Transplant complication	28.1	Transplant complication	21.9
Other infection	16.0	Other	11.7
Other	9.4	Other infection	10.2
Respiratory infection	7.3	Respiratory infection	9.8
Genito-urinary and breast	5.0	Gastro-intestinal	9.8
Bacteremia, viremia and septicemia	4.4	Genito-urinary and breast	5.1
Gastro-intestinal	4.4	Skin and musculoskeletal	5.1
Metabolic, endocrine, nutritional	3.8	Metabolic, endocrine, nutritional	3.5
Electrolyte, acid-base & volume depletion	2.5	Electrolyte, acid-base & vol. depletion	3.2
Immune and hematologic	2.5	Respiratory	3.2

HR 7.4 Top ten causes of rehospitalization among heart recipients transplanted in 2008 with Medicare primary coverage

Transplant recipients, 2008, with Medicare as the primary payer at transplant. Reasons for rehospitalization determined from Medicare claims, denominator for percentages includes only those re-hospitalized.

Medicare data

		# patients	Total costs		PPPY costs	
			Part A	Part B	Part A	Part B
All patients		904	215,261,230	27,321,527	264,994	33,634
Age	0-11	*	*	*	*	*
	12-17	*	*	*	*	*
	18-34	45	11,615,361	1,346,347	305,734	35,438
	35-49	154	36,898,646	4,704,291	262,816	33,507
	50-64	399	95,117,399	12,197,767	261,304	33,509
	65+	304	69,941,079	9,014,496	261,052	33,646
Sex	Male	697	164,541,493	20,992,625	260,769	33,270
	Female	207	50,719,738	6,328,902	279,695	34,901
Race	White	629	149,153,877	18,866,651	261,609	33,091
	Black	180	42,688,935	5,634,648	274,360	36,214
	Hispanic	75	18,625,061	2,236,018	273,018	32,777
	Asian/Pac. Isl.	14	3,187,437	386,088	246,434	29,850
	Other/unk.	*	*	*	*	*
Primary cause of disease	Coron. artery dis.	423	101,795,695	12,706,390	268,833	33,556
	Cardiomyopathy	430	100,493,855	13,059,818	255,743	33,235
	Congenital dis.	19	5,178,333	519,682	392,542	39,394
	Valvular disease	18	3,939,561	550,376	234,766	32,798
	Other/unk.	14	3,853,786	485,261	358,560	45,149

HR 7.5 Total and per-person per-year (PPPY) Medicare costs (\$) among heart transplant recipients in the first post-transplant year

Costs among recipients transplanted in 2008 and 2009 who had Medicare as the primary payer at the time of transplant. First year costs include the transplant hospitalization. Costs incurred after a transplant failure are excluded. Values for cells with 9 or fewer patients are suppressed.

		# patients	Total costs		PPPY costs	
			Part A	Part B	Part A	Part B
All patients		376	8,744,418	5,344,505	23,671	14,468
Age	0-11	*	*	*	*	*
	12-17	*	*	*	*	*
	18-34	18	361,264	204,893	20,015	11,352
	35-49	71	1,829,046	1,127,822	26,230	16,174
	50-64	173	4,740,020	2,474,462	27,909	14,569
	65+	112	1,718,713	1,507,747	15,633	13,714
Sex	Male	282	6,692,421	3,918,017	24,145	14,135
	Female	94	2,051,997	1,426,488	22,248	15,466
Race	White	255	5,312,175	3,650,250	21,233	14,590
	Black	75	2,099,023	1,056,383	28,302	14,244
	Hispanic	39	1,272,609	575,628	33,449	15,130
	Asian/Pac. Isl.	*	*	*	*	*
	Other/unk.	*	*	*	*	*
Primary cause of disease	Coron. artery dis.	176	4,004,437	2,485,618	23,278	14,449
	Cardiomyopathy	187	4,555,854	2,697,376	24,714	14,632
	Congenital dis.	*	*	*	*	*
	Valvular disease	*	*	*	*	*
	Other/unk.	*	*	*	*	*

HR 7.6 Total and per-person per-year (PPPY) Medicare costs (\$) among heart transplant recipients in the second post-transplant year

Costs among recipients transplanted in 2008 who had Medicare as the primary payer at the time of transplant. The second post-transplant year runs from 366 to 730 days after transplant. Costs incurred after a transplant failure are excluded. Values for cells with 9 or fewer patients are suppressed.

Medicare data

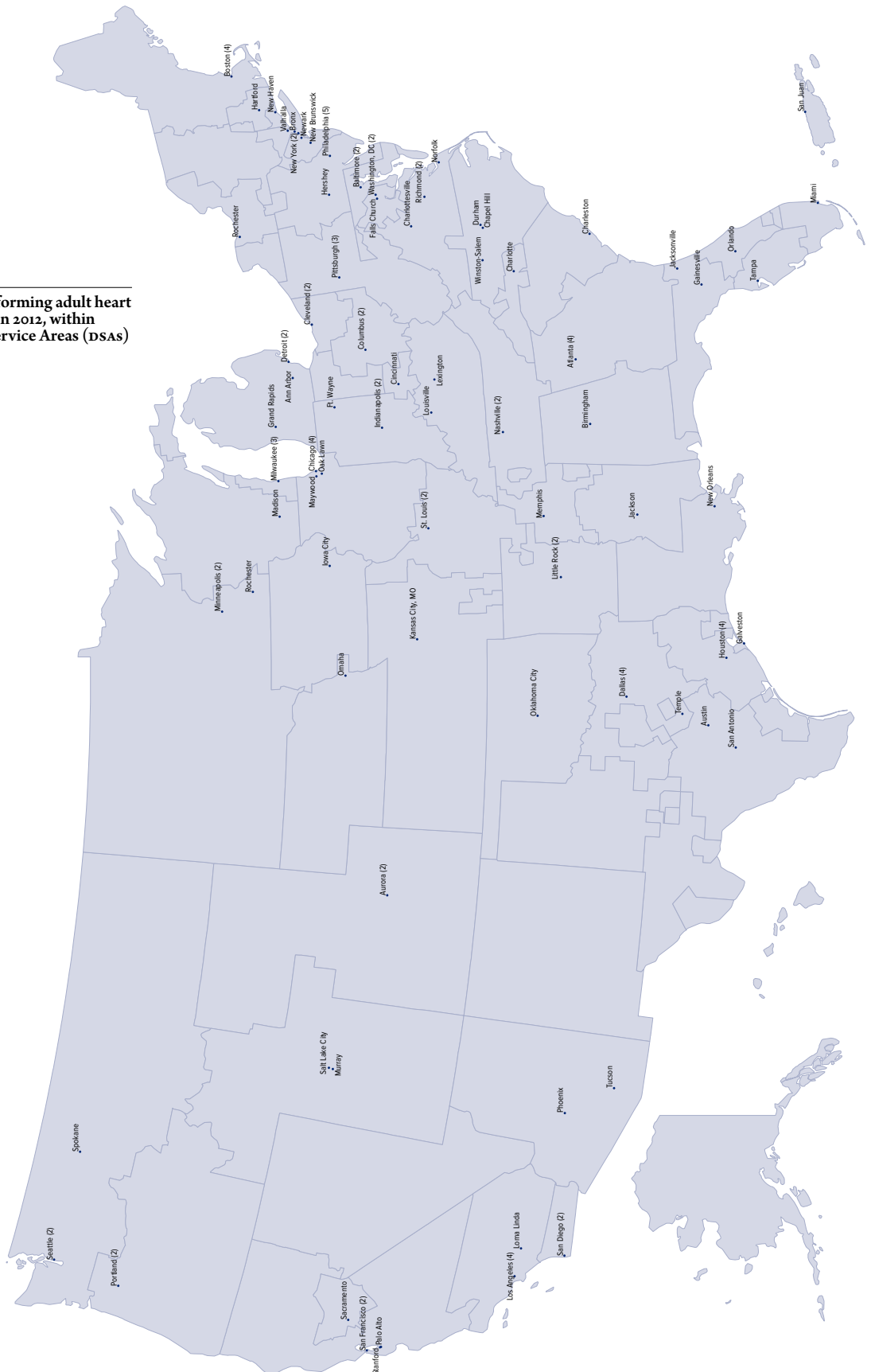
Total costs										
		2008 total costs			2009 total costs			2010 total costs		
		# patients	Part A	Part B	# patients	Part A	Part B	# patients	Part A	Part B
All patients		12,228	273,002,263	82,649,717	12,485	295,983,294	98,915,517	12,783	311,817,476	100,072,579
Age	0-11	35	2,383,768	270,417	34	1,029,470	399,041	44	1,664,842	410,835
	12-17	44	739,576	171,666	47	869,202	262,211	49	1,191,674	277,932
	18-34	705	17,777,422	4,400,795	749	17,349,792	5,375,256	788	22,413,225	5,783,450
	35-49	2,592	50,590,887	15,314,323	2,704	56,815,216	18,937,292	2,757	57,130,238	18,675,818
	50-64	7,314	150,461,215	48,150,906	7,338	161,598,418	55,877,140	7,399	164,819,127	55,600,202
	65+	1,538	51,049,395	14,341,611	1,613	58,321,196	18,064,577	1,746	64,598,371	19,324,342
Sex	Male	9,761	208,851,479	64,620,773	9,955	233,851,989	77,959,642	10,156	243,888,427	78,891,633
	Female	2,467	64,150,784	18,028,945	2,530	62,131,305	20,955,875	2,627	67,929,049	21,180,946
Race	White	9,760	199,479,895	64,022,322	9,886	218,717,251	75,589,883	9,999	227,450,966	75,973,396
	Black	1,555	47,147,633	12,048,401	1,628	52,277,403	15,077,292	1,736	53,923,588	15,662,692
	Hispanic	671	20,656,985	4,939,650	710	19,107,796	6,330,281	766	20,768,420	6,156,476
	Asian/Pacific Islander	171	3,939,655	1,229,077	191	4,599,543	1,373,615	203	6,843,163	1,725,373
	Other/unlk.	71	1,778,094	410,268	70	1,281,302	544,446	79	2,831,338	554,642
Primary cause of disease	Coronar artery dis.	6,215	137,728,716	42,945,029	6,240	143,570,961	49,746,702	6,296	151,827,311	50,011,716
	Cardiomyopathy	5,312	119,065,358	34,972,552	5,507	132,745,035	42,880,132	5,719	139,545,710	44,051,172
	Congenital disease	205	5,460,775	1,329,914	219	5,566,505	1,709,231	237	6,037,871	1,778,519
	Valvular disease	313	6,248,450	2,192,025	323	7,843,713	2,902,435	334	7,734,098	2,791,670
	Other/unlk.	183	4,498,963	1,210,197	196	6,257,080	1,677,017	197	6,672,485	1,439,502

Total costs										
		2008 total costs			2009 total costs			2010 total costs		
		# patients	Part A	Part B	# patients	Part A	Part B	# patients	Part A	Part B
All patients		12,228	23,878	7,229	12,485	25,534	8,533	12,783	26,284	8,435
Age	0-11	35	72,283	8,200	34	31,170	12,082	44	39,795	9,820
	12-17	44	18,410	4,273	47	18,926	5,709	49	25,559	5,961
	18-34	705	27,030	6,691	749	24,655	7,639	788	30,617	7,900
	35-49	2,592	20,654	6,252	2,704	22,390	7,463	2,757	22,055	7,210
	50-64	7,314	21,910	7,012	7,338	23,635	8,173	7,399	23,843	8,043
	65+	1,538	36,849	10,352	1,613	40,655	12,593	1,746	41,948	12,549
Sex	Male	9,761	22,860	7,073	9,955	25,291	8,431	10,156	25,885	8,373
	Female	2,467	27,930	7,849	2,530	26,490	8,935	2,627	27,823	8,676
Race	White	9,760	21,786	6,992	9,886	23,751	8,209	9,999	24,399	8,150
	Black	1,555	32,820	8,387	1,628	35,304	10,182	1,736	34,330	9,972
	Hispanic	671	33,426	7,993	710	28,967	9,597	766	29,280	8,680
	Asian/Pacific Islander	171	25,303	7,894	191	25,968	7,755	203	35,867	9,043
	Other/unlk.	71	26,750	6,172	70	19,521	8,295	79	40,070	7,849
Primary cause of disease	Coronar artery dis.	6,215	23,720	7,396	6,240	24,845	8,609	6,296	25,995	8,563
	Cardiomyopathy	5,312	23,961	7,038	5,507	25,907	8,369	5,719	26,328	8,311
	Congenital disease	205	28,965	7,054	219	26,779	8,223	237	26,754	7,881
	Valvular disease	313	20,971	7,357	323	25,847	9,564	334	24,270	8,760
	Other/unlk.	183	26,322	7,080	196	35,181	9,429	197	37,427	8,074

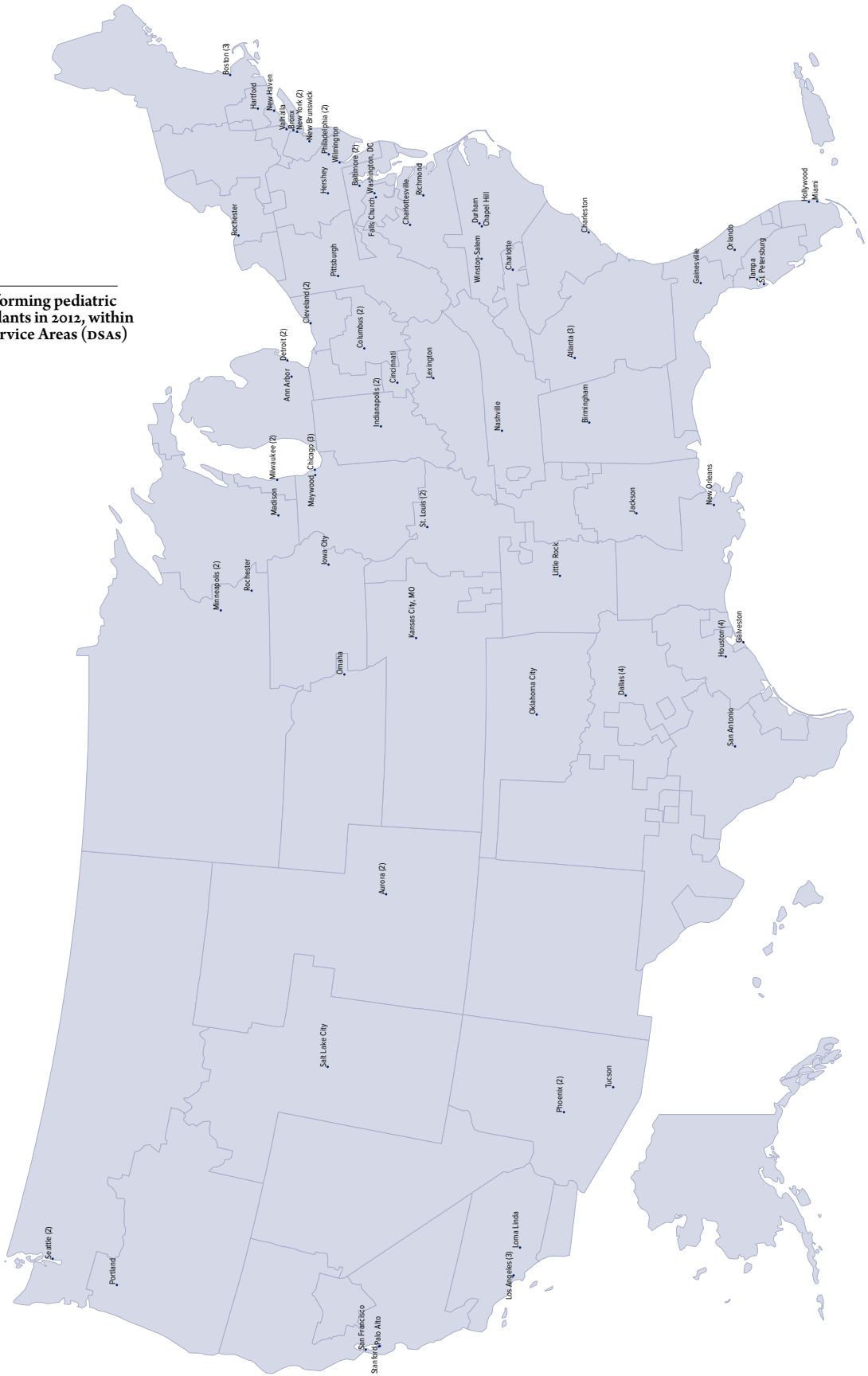
HR 7.7 Total calendar-year Medicare costs (\$) spent on heart transplant recipients, 2008, 2009, & 2010

Costs paid by Medicare in each calendar year among recipients alive with graft function in the given year, regardless of Medicare eligibility at the time of transplant. Costs incurred after transplant failure are excluded.

HR 8.1 Centers performing adult heart transplants in 2012, within Donation Service Areas (DSAs)



HR 8.2 Centers performing pediatric heart transplants in 2012, within Donation Service Areas (DSAs)



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OPTN/SRTR 2012 Annual Data Report:

lung

ABSTRACT Lung transplants are increasingly used as treatment for end-stage lung diseases not amenable to other medical and surgical therapies. Lungs are allocated to adult and adolescent transplant candidates on the basis of age, geography, blood type compatibility, and the Lung Allocation Score, which reflects risk of wait-list mortality and probability of posttransplant survival. The overall median waiting time in 2012 was 4 months, and 65.3% of candidates underwent transplant within 1 year of listing; however, this proportion varied greatly by donation service area. Unadjusted median survival of lung transplant recipients was 5.3 years in 2012, and median survival conditional on living for 1 year posttransplant was 6.7 years. Among pediatric lung candidates in 2012, 32.1% were wait-listed for less than 1 year, 17.9% for 1 to less than 2 years, 16.7% for 2 to less than 4 years, and 33.3% for 4 or more years. Both graft and patient survival have continued to improve; survival rates for recipients aged 6-11 years are better than for younger recipients. Compared with recipients of other solid organ transplants, lung transplant recipients experienced the highest rates of rehospitalization for transplant complications: 43.7 per 100 patients in year 1 and 36.0 in year 2.

KEY WORDS End-stage lung diseases, Lung Allocation Score, lung transplant, organ allocation, transplant outcomes.

I still catch myself on the street, or at a cafe, or wherever, and I'll think about how wonderful it feels to breathe – and I'll start welling up... I've had beautiful (donated) lungs for over 13 years now. I still think about them every single day, and about my donor.

Steve, lung/kidney recipient

Introduction

Lung transplants are increasingly used as treatment for end-stage lung diseases that are no longer amenable to other medical and surgical therapies. As of June 30, 2012, more than 10,000 recipients were alive with a lung transplant (Figure 5.5). Lungs are allocated to US transplant candidates primarily on the basis of age, geography, blood type (ABO) compatibility, and the Lung Allocation Score (LAS). Implemented in 2005, the LAS calculation is a score that reflects risk of wait-list mortality while avoiding transplants that have a very poor likelihood of survival.

The LAS applies to adolescent (aged 12 to 17 years) and adult (aged 18 years or older) candidates. Therefore, the adult section below includes data for candidates and recipients aged 12 years or older; the pediatric section reports data for candidates and recipients who are less than 12 years old.

As part of the development of the LAS system, pulmonary diagnoses of candidates (aged 12 years or older) were categorized into four main groups based on survival probability and pathophysiology of the underlying disease. The four groups are: Group A, obstructive lung disease (e.g., chronic obstructive lung disease/emphysema); Group B, pulmonary vascular disease (e.g., idiopathic pulmonary arterial hypertension); Group C, cystic fibrosis and immunodeficiency disorders; and Group D, restrictive lung disease (e.g., idiopathic pulmonary fibrosis). The first comprehensive revision of the LAS calculation was approved by the OPTN Board of Directors in November 2012 and will be implemented pending programming. This revision includes modifications to the variables included in the LAS calculation and the relative weight of the variables used to predict risk of death without a transplant and after transplant. The revised LAS will further improve the survival predictability for all diagnostic groups; these effects will be most notable for candidates in Group B.

Adult lung transplant

WAITING LIST

After an initial decline immediately following implementation of the LAS system in May 2005, the number of new patients added to the waiting list grew steadily until 2010; however,

this trend appears to have reached a plateau (Figure 1.1). The number of inactive candidates has continued to decline every year since implementation of the LAS and was at an all-time low of 317 on December 31, 2012 (Figure 1.1). This steady decrease in inactive candidacy may indicate that candidates are being more appropriately chosen for the waiting list and those at risk of being designated as inactive because of becoming too sick for transplant are undergoing transplant more efficiently.

The LAS system changed the character of the waiting list. Since its implementation, candidates on the waiting list are increasingly older, are more likely to be from diagnosis Group D, and are sicker (Figure 1.2). Candidates aged 65 years or older continue to compose an increasing proportion of the waiting list. In 2012, 25.9% of the waiting list was aged 65 years or older compared with 5.8% in 2004 (the last full year before implementation of the LAS). In contrast, the proportion of candidates aged 18 to 34 years decreased from 15.2% of the waiting list in 2004 to 11.8% in 2012, the group aged 35 to 49 years decreased from 23.5% to just 13.5%, and the group aged 50 to 64 years decreased from 52.9% to 47.9% of the waiting list. The proportion of Group D candidates continues to increase every year and was at an all-time high of 49.5% of the waiting list in 2012. All other diagnostic groups represent a smaller proportion of the waiting list now than they did in 2004. The LAS distribution on the waiting list is also trending to higher scores; for example, 12.7% of the candidates had an LAS of 50 to 100 in 2006 (the first full year after implementation of the LAS) in contrast to 22.5% in 2012. The use of retransplant as an option has remained relatively stable despite the potential for a high LAS and increased access to transplant for this population. On December 31, 2012, 3.0% of those on the waiting list had been listed for retransplant (Figure 1.3). Candidates who need a lung transplant are rarely listed for multi-organ transplant; the most common combinations are heart-lung transplant (2.0%) and liver-lung transplant (0.5%) (Figure 1.3).

Since implementation of the LAS, transplant rates have increased for all candidates awaiting a lung transplant; however, that increase is most dramatically illustrated in candidates aged 65 years or older and those in diagnosis Group D (Figure

1.4). Overall median waiting time for candidates listed for lung transplant in 2012 was 4.0 months, varying from 3.1 months for Group D patients to a median that was not observed in Group B patients. Median months to transplant for Group B patients listed in 2011 was 9.7 months (Figure 1.8). While 65.3% of lung transplant candidates underwent transplant within 1 year of listing, the proportion of candidates undergoing lung transplant varied greatly by donation service area (DSA) ranging from 37.5 to 93.5% for those with at least 10 listings (Figure 1.9).

Wait-list mortality rates by candidate demographics have changed dramatically since implementation of the LAS. The LAS was originally implemented to minimize wait-list mortality while considering the probability of posttransplant survival. This methodology also de-emphasized time on the waiting list, effectively removing any incentive for early listing. As a result of the changing priorities in the new allocation model, candidates being listed for transplant have more advanced lung disease at listing than in previous years. After the initial decline in mortality rates, wait-list mortality rates are on the rise again and were at 15.4 per 100 wait-list years in 2010-2012, trending toward the high mortality rates preceding the LAS (Figure 1.10). Candidates aged 12 to 17 years had the highest wait-list mortality, at 19.7 deaths per 100 wait-list years, followed by those aged 18 to 34 years. Those in diagnosis Group D not only compose the largest proportion of the waiting list but also had the highest wait-list mortality rates. In 2010-2012, those in Groups B and C had the next highest mortality rates; however, Group C has had a higher mortality than Group B at all other time points from the pre-LAS era to the post-LAS era. Minority candidates (Asian, Hispanic, and black) have higher mortality rates than whites – a trend that is not easily explained and will need further analysis. Candidates with an LAS of 50 or higher have a mortality risk that is nearly 10 times greater than that for candidates whose LAS is less than 50. Those with a score of less than 40 have nearly the same mortality rate, ranging from 4.5 to 8.6 deaths per 100 wait-list years.

DONATION

Deceased donors are the primary source of lungs for transplant, accounting for 99.9% of all transplants. Deceased lung

donation rates have steadily increased over the past decade. While overall donation rates have increased, increases have been larger for certain demographic groups than for others. Specifically, from 2000 to 2011, rates among donors aged 15 to 34 years increased from 5.8 to 12.2 donations per 1000 deaths; compared with other age groups, this age group continues to have the highest donation rates of lungs for transplant (Figure 2.1). Lungs from donors aged 55 years or older were rarely used, with donation rates in 2011 of 0.5 and 0.04 for donors aged 55 to 64 years and those aged 65 to 74 years, respectively (Figure 2.1). Donation rates vary by race as well. In the last 10 years, donation rates for Hispanics are almost twice the rate for whites and are the highest rates of all racial groups. Geographically, donation rates continue to vary by state. Alaska, District of Columbia, Delaware, Maryland, and Kansas had the highest deceased donor lung donation rates in the US in 2009-2011 (Figure 2.2).

The number of lungs recovered and transplanted per deceased donor has been steadily increasing, from 0.25 lungs recovered per donor in 2000 to 0.39 lungs recovered per donor in 2012 (Figure 2.1, Deceased Organ Donation chapter). Similarly, the rate of lungs transplanted per donor has increased, from 0.25 in 2000 to 0.37 in 2012 (Figure 3.1, Deceased Organ Donation chapter). Discard rates appear to be increasing particularly in the past 10 years, going from 5.5% to 7.3% of lungs recovered (Figure 2.3). However, this is in the setting of more aggressive recovery of organs; in 2002 a total of 1138 lungs were recovered compared with 1939 in 2012. With utilization of new lung repair technologies currently under investigation in the US, such as ex vivo lung perfusion, perhaps the number of lungs recovered and ultimately transplanted will increase if these techniques are found to be effective and can be widely used by US transplant programs.

TRANSPLANT

In 2012, 1783 lung transplants were performed, a decline as compared with 1849 and 1811 in 2011 and 2010, respectively (Figure 3.1). This trend was not due to increased relative percentage of bilateral transplants, as they too decreased from 70% of transplants in 2010 and 2011 to 68% in 2012. However,

the overall utilization of bilateral lung transplants has grown from a total of 49.9% of all lung transplants in 2002 to 67.3% in 2012 (Figure 3.7), a trend that precedes implementation of the LAS. Retransplant rates have also increased, compared with the pre-LAS era; however, they have remained stable since implementation of LAS and still account for a small percentage of all transplants in 2012 at 5.5% (Figure 3.5).

Since implementation of the LAS, candidates aged 65 years or older, men, and those in diagnosis Group D have composed a larger proportion of patients undergoing transplant each year (Figure 3.2). In 2004, only 6.8% of the transplants in the US were performed in recipients aged 65 years or older. By 2012, recipients aged 65 years or older composed 26.3% of US lung recipients. During that same period, all recipients less than 65 years old received a smaller proportion of lung transplants compared with the pre-LAS era. Part of this shift reflects the aging of the US population. Also, LAS policy priorities, such as increased transplant access for patients who are at increased risk of mortality, (e.g., those in Group D, who tend to be older), may be reinforcing this shift to older recipient age. The proportion of female lung transplant recipients has also markedly decreased since implementation of the LAS. In 2004, female candidates received 50.1% of all lung transplants, but by 2012 women represented only 42.0% of lung transplant recipients. The trend appears stable in the post-LAS era. This trend cannot be explained by the decline in female lung transplant candidates, as they continue to represent nearly 60% of the waiting list (Figure 1.3). However, it is possible that the higher prevalence of men with pulmonary fibrosis—the predominant diagnosis in Group D patients, who have preferential access to transplant as a result of their high LAS scores—can explain this trend. Minority recipients (Asian, Hispanic, and black) are receiving a smaller number of transplants, but they represent a small proportion of the waiting list (Figures 3.2 and 1.2). During 2010-2012, these candidates experienced slightly higher mortality rates compared with whites: 20.8 for Asian, 18.7 for Hispanic, and 17.2 for black versus 14.8 deaths per 100 wait-list years for white candidates (Figure 1.10).

Lung transplant recipients are undergoing transplant with higher LAS scores (Figures 3.2 and 3.4). When the LAS system

was implemented, the median LAS at transplant was 36.6; it increased to the median value of 40.7 in 2010 and has remained stable since then (Figure 3.4). The distribution of the LAS has also shifted, with an increase in the 75th percentile scores indicating that more candidates are being transplanted with higher LAS. The combined observed trends of increasing LAS on the waiting list (Figure 1.2), increasing LAS at transplant (Figure 3.4), and increasing wait-list mortality (Figure 1.10) very likely support the notion that sicker patients are being listed for lung transplant in the post-LAS era.

IMMUNOSUPPRESSION

The growing interest in antibody-mediated rejection has not yet resulted in significant changes in choice of initial immunosuppression in lung transplant recipients. The triple-drug regimen of a calcineurin inhibitor, an anti-metabolite, and a steroid is still the norm. Since 1998, use of tacrolimus as the primary calcineurin inhibitor has steadily increased; today, it is used in more than 90% of lung transplant recipients (Figure 3.8). Mycophenolate remains the predominant anti-metabolite used in lung transplant recipients, and its use continues to grow annually. Steroid use is also virtually universal and extends from the immediate posttransplant period through at least 1 year after transplant. Mammalian target of rapamycin (mTOR) inhibitors are used rarely, if at all, immediately after transplant; however, it is reported to be used in a small percentage of patients (less than 10%) in the first year after transplant. No induction was used after lung transplant in most lung transplant recipients from 1998 to 2005; however, that trend changed starting in 2006. In 2012, 55% of patients received some form of induction compared with 23% of patients in 1998. For patients who did receive an induction agent, interleukin-2 receptor antagonists were the primary agents chosen, with a minority of patients receiving a T-cell depleting agent (Figure 3.8).

DONOR/RECIPIENT HLA MATCHING

The significance of antibody-mediated rejection is well recognized in other solid organ transplants, but its role in graft dysfunction after lung transplant is not well understood and

is a subject of increasing interest in the scientific community. While there is no strong consensus regarding its diagnostic characteristics, it is accepted that closer immunologic or HLA match between a donor and a recipient will minimize risk of antibody-mediated and cellular rejection. However, the past decade has seen an apparent trend toward more liberally performing transplants with higher PRA (Figure 3.2) and HLA (at A, B, and DR loci) mismatches (Figure 4.1), particularly since implementation of the LAS. It is unclear whether this noted trend is the result of recent changes in methods that make the detection of circulating anti-HLA antibodies more sensitive, or whether it reflects an intentional practice trend at transplant centers.

DONOR/RECIPIENT SEROLOGIC MATCHING

In approximately 70% of lung transplants performed from 2008 to 2012, donor cytomegalovirus (CMV) status and recipient CMV status were either matched or CMV-positive candidates received CMV-negative lungs (Figure 4.2). This practice decreases the risk of a CMV-negative recipient seroconverting to CMV and suffering its potential known consequences, such as CMV viremia, pneumonia, or increased risk of developing bronchiolitis obliterans syndrome. However, 24.5% of lung transplants were from a CMV-positive donor to a CMV-negative recipient. Similarly, donors and recipients are often matched on the basis of Epstein-Barr virus (EBV) status; only 10.3% of lung transplants were from an EBV-positive donor to an EBV-negative recipient (Figure 4.3). This contrast between EBV and CMV trends is explained by 76.8% of transplant candidates being positive for EBV but only 54.0% of candidates being positive for CMV.

OUTCOMES

Since 2007, median survival for lung transplant recipients, including survival conditional on living 1 year after transplant, has remained stable (Figure 5.4). Unadjusted median survival for all lung transplant recipients is now 5.3 years, while 1-year conditional median survival is 6.7 years. Short-term survival (30-day and 1-year) has in fact improved; however, 3-year survival has plateaued and 5-year survival has decreased when

comparing post-LAS with pre-LAS survival outcomes (Figure 5.2). However, given the relatively short follow-up period since implementation of the LAS, it may be that 3- and 5-year survival data do not represent stable trends. Survival is lowest among recipients aged 65 years or older (Figure 5.1), those with LAS greater than 50, and possibly for those in diagnosis Group B (Figure 5.3). It is notable that patients with higher LAS are increasingly undergoing transplant (Figure 3.4) and that patients aged 65 years or older are undergoing transplant at increasingly higher rates than those in other age categories (Figure 1.4). If these transplant trends continue, it is reasonable to expect a continued decline in overall survival or at least in long-term survival of lung transplant recipients.

Procedure choice appears to affect survival as well, with patients receiving a left single lung transplant having the worst survival compared with those receiving single right and bilateral lung transplants (log-rank $P < 0.0001$). However, it is important to keep in mind that these registry data regarding single and bilateral lung transplant have not been adjusted for age, LAS, and diagnoses—variables that may mediate the observed survival differences. Patients undergoing transplant for diagnoses that do not require a bilateral transplant (e.g., alpha-1 antitrypsin deficiency, chronic obstructive pulmonary disease, and idiopathic pulmonary fibrosis), and who therefore receive both types of transplant with some frequency, also have improved survival when they receive a bilateral lung transplant compared with a single lung transplant (log-rank $P < 0.0001$).

Five years after transplant, the vast majority of surviving recipients require no assistance in their activities of daily living (Figure 5.7). However, several complications can adversely affect the health of transplant recipients and likely contribute to mortality. Five years after transplant, of recipients in 2005-2007, 66.7% were reported to have drug-treated hypertension; 53.8% reported drug-treated hyperlipidemia; 49.8 reported some degree of renal dysfunction; 42.5% reported diabetes, and 18.3% were diagnosed with a malignancy (Figure 5.7). These complications are presumed to stem in large part from the long-term use of immunosuppressive medications. Despite the rather aggressive immunosuppression of lung transplant patients, bronchiolitis obliterans or chronic rejection was reported in the

first year in 7.9% of recipients. By 5 years, 43% of patients were reported to have bronchiolitis obliterans. However, graft failure is not the primary cause of death in lung transplant recipients; rather, it is infection (Figure 5.9). Graft failure, other respiratory causes (e.g., respiratory failure, acute respiratory distress, pulmonary embolism), cardiovascular/cerebrovascular disease, and malignancy are the other frequently reported causes of death in this population.

Pediatric Lung Transplant

WAITING LIST

Since 1998, the number of new child candidates (aged 0 to 11 years) added each year to the lung transplant waiting list has consistently decreased, with 25 total additions in 2012 (Figure 6.1). Among prevalent lung transplant candidates, those listed as inactive continue to outnumber those listed as active. The age distribution of child candidates on the lung transplant waiting list has changed over time due to changes in the diagnoses for which lung transplant is indicated and also due to earlier detection and more aggressive testing for diseases such as surfactant deficiencies. The proportion of candidates less than 1 year old has steadily increased, from 7.4% in 2002 to 15.4% in 2012 (Figure 6.2). In 2012, 28.2% of candidates were aged 1 to 5 years and 56.4% were aged 6 to 11 years. As seen in all pediatric transplantation, the ethnic distribution of candidates on the waiting list has changed, with increasing representation of Hispanic patients, who accounted for 17.9% of candidates in 2012. Among pediatric lung candidates in 2012, 32.1% were on the waiting list for less than 1 year, 17.9% for 1 to less than 2 years, 16.7% for 2 to less than 4 years, and 33.3% for 4 or more years (Figure 6.2).

Of patients removed from the waiting list in 2012, 47.1% were removed from the waiting list because they received a transplant, 32.4% because of death, and 17.6% because of improved condition (Figure 6.3). Looking at 3-year outcomes for pediatric lung transplant candidates listed in 2009, 60% received a transplant, 15% died, 15% were still waiting, and 10% were removed from the list for reasons other than transplant or death (Figure 6.4). The overall lung transplant rate was 78 per 100 wait-list years in 2012, 77 in candidates aged less than

6 years old, and 94 in candidates aged 6 to 11 years (Figure 6.5). Pretransplant mortality in 2012 was 17.7 per 100 wait-list years; the rates were 2-fold higher in patients less than 6 years old compared with patients aged 6 to 11 years: 29.4 versus 13.3 per 100 wait-list years, respectively (Figure 6.6).

TRANSPLANT

In 2012, the total number of lung transplants in candidates aged 0 to 11 years was 12: 4 in recipients less than 1 year old, 4 in recipients aged 1 to 5 years, and 4 in recipients aged 6 to 11 years (Figure 6.7). Five percent of recipients had a history of a prior transplant (Figure 6.8). Lung transplants were part of a multi-organ transplant in 8.8% of cases in 2012, with heart being the most common other organ at 5.9% (Figure 6.9). Looking at the past decade of lung transplantation in child recipients, there has been a shift toward younger recipients; in 2010-2012, nearly 60% of recipients were less than 6 years old, compared with 39% in 2000-2002 (Figure 6.10). The etiology of lung disease among child lung transplant recipients has changed over time, with a decrease in the proportion of recipients with cystic fibrosis and pulmonary hypertension and an increase in pulmonary fibrosis and "other diagnoses," such as surfactant protein B deficiency and bronchopulmonary dysplasia, which now account for 36.8%. Among child lung transplant recipients in 2010-2012, 57.9% waited less than 3 months for transplant compared with 37.3% in 2000-2002. Among the 2010-2012 recipients, 33.3% were in the intensive care unit immediately before transplant, 38.6% were on the ventilator, and 3.5% were receiving extracorporeal membrane oxygenation. The procedure of choice was bilateral sequential transplant, which was performed in 87.7% of patients. Medicaid coverage for pediatric lung transplant has increased, with a corresponding decrease in private insurance coverage (Figure 6.10).

Posttransplant lymphoproliferative disorder (PTLD) is a marked concern in pediatric transplantation. Among child lung transplant recipients in 2008-2012, 60% were EBV-negative and 39% were EBV-positive (Figure 6.11). The highest risk for EBV infection and PTLD occurs in EBV-negative recipients of EBV-positive donor organs; this occurred in 33% of recipients

in 2008-2012 (Figure 6.11). The incidence of PTLD among EBV-negative recipients was 14.4% at 5 years after transplant, compared with 2.8% among EBV-positive recipients (Figure 6.13).

Among child lung transplant recipients in 2008-2012, 63.1% were CMV-negative and 35.7% were CMV-positive (Figure 6.12). The combination of a CMV-positive donor and CMV-negative recipient occurred in 35.7% of recipients.

IMMUNOSUPPRESSION

The trends in immunosuppression for lung transplant recipients less than 12 years old are similar to those in recipients aged 12 years or older (Figure 6.15). In 2012, tacrolimus was used in 85.7% of child lung transplant recipients, with no cyclosporine use reported; similarly, mycophenolate was used in 85.7% and no azathioprine use was reported. Steroids were used at the time of transplant in 92.9% of recipients and in almost all at 1 year after transplant. The past decade has seen a shift from no induction therapy to an increasing use of interleukin-2 (IL-2) receptor antagonist therapy (Figure 6.15). In 2012, 50% of recipients received IL-2 receptor antagonist therapy for induction, 28.6% received T cell depleting agents, and 21.4% reported no induction therapy.

OUTCOMES

Both graft and patient survival have continued to improve over the past decade. For transplants performed in 2007-2008, patient survival was 96.3% at 30 days, 87.0% at 1 year, 60.1% at 3 years, and 49.0% at 5 years (Figure 6.16).

In 2008-2011, rehospitalization occurred in just over half of pediatric lung transplant recipients at 1 year (Figure 6.14). Post-transplant complications for child lung transplant recipients are similar to adult recipients and include hypertension, renal dysfunction, diabetes, bronchiolitis obliterans syndrome, and malignancy. Most child lung transplant recipients are reported as “fully active” at 1 year after transplant.

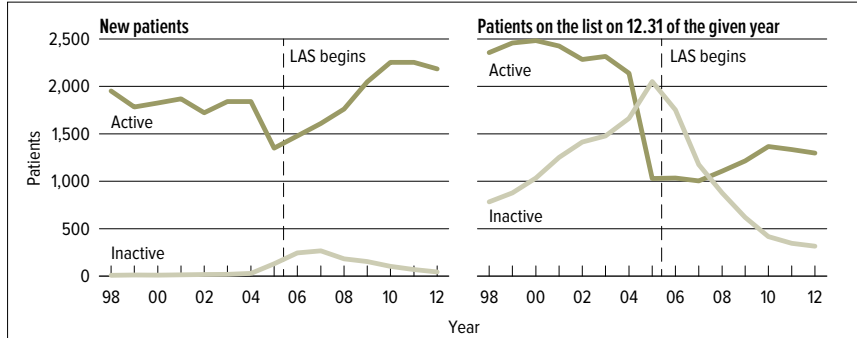
Among child lung recipients who underwent transplant in 2006-2011, the incidence of acute rejection was 17% within 1 year and 21% within 2 years after transplant (Figure 6.17). Figure 6.18 shows the variations in 5-year recipient survival by age, sex, race, and primary diagnosis. Recipients aged 6 to 11

years have higher survival rates compared with younger recipients. The diagnosis of pulmonary hypertension is associated with higher survival rates than cystic fibrosis or the “other” category, which includes diagnoses such as pulmonary fibrosis, bronchiolitis obliterans, and bronchopulmonary dysplasia.

ECONOMICS

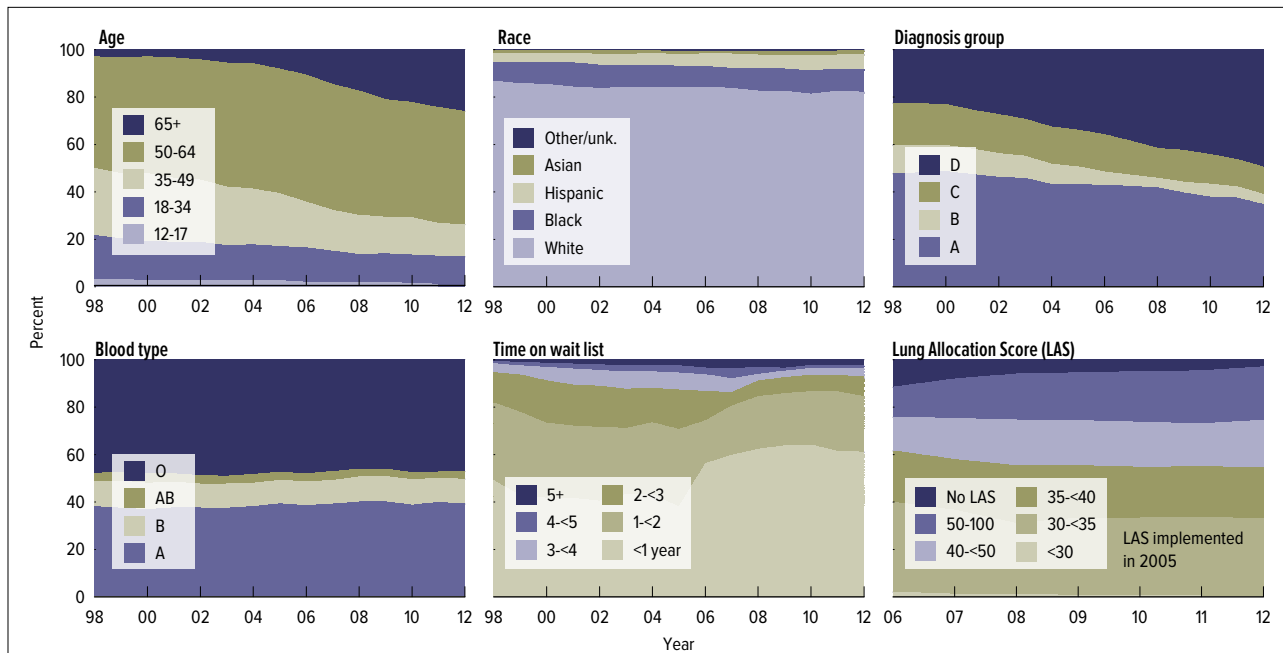
Medicare paid for some or all of the care for more than 50% of lung transplants in 2010 (Figure 7.1). For lung recipients with primary Medicare coverage, average reimbursement from transplant through 1 year after transplant was \$207,013 for Part A and \$28,862 for Part B (Figure 7.5), totaling \$235,875; this is approximately three times the Medicare Parts A and B expenditure for a kidney transplant recipient (Figure 8.5, Kidney chapter) and is the least expensive of heart, lung, and intestine transplant (Figure 7.5, Heart chapter; Figure 5.5, Intestine chapter). Rehospitalization is common after lung transplant with relatively high rates of rehospitalization in the first year after transplant (Figure 7.2), dropping by half in the second year (Figure 7.3). Primary causes for rehospitalization during the first and second years after transplant are for transplant complications and infections (Figure 7.4). Compared with kidney, pancreas, liver, intestine, and heart recipients, lung transplant recipients experienced the highest rates of rehospitalization for transplant complications with 43.7 per 100 patients in year 1 and 36.0 per 100 patients in year 2 (Figure 7.4; compare with: Figure 8.4, Kidney chapter; Figure 6.4, Pancreas chapter; Figure 8.4, Liver chapter; Figure 5.4, Intestine chapter; Figure 7.4, Heart chapter). Annual costs after the first year are smaller for Medicare Parts A and B, averaging \$38,253 and \$13,425, respectively, during year 2 (Figure 7.6), totaling \$51,678. Additional costs not accounted for here include reimbursement to hospitals for the transplant portion of the Medicare Cost Report and Medicare Part D. Including estimates for these brings average Medicare cost to approximately \$300,000 in the first year after transplant and approximately \$60,000 in subsequent years. Lung transplant recipients account for 6% of all Medicare Parts A and B expenditures after solid organ transplant; in 2010 this totaled \$233 million, or \$41,429 per patient (Figure 7.7).

wait list



LU 1.1 Adult patients waiting for a lung transplant

Patients waiting for a transplant. A “new patient” is one who first joins the list during the given year, without having listed in a previous year. However, if a patient has previously been on the list, has been removed for a transplant, and has relisted since that transplant, the patient is considered a “new patient.” Patients concurrently listed at multiple centers are counted only once. Those with concurrent listings and active at any program are considered active; those inactive at all programs at which they are listed are considered inactive.



LU 1.2 Distribution of adult patients (active) waiting for a lung transplant

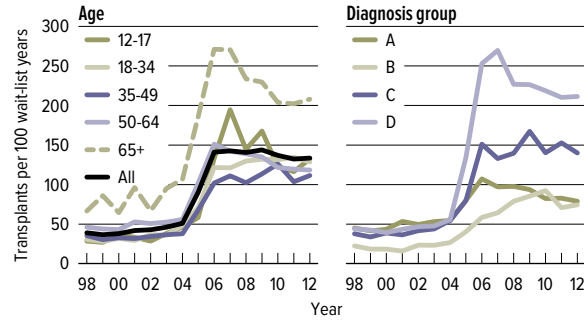
Patients waiting for a transplant any time in the given year. Age determined on the earliest of listing date or December 31 of the given year. Concurrently listed patients are counted once. Patients first listed prior to LAS implementation may remain score-less after 2005 due to missing data among elements required to compute LAS. LAS is the first known in the given year.

	Level	2002		2007		2012	
		N	%	N	%	N	%
Age	12-17	94	2.5	40	1.8	23	1.4
	18-34	608	16.5	314	14.4	167	10.3
	35-49	1,113	30.2	523	24.0	235	14.5
	50-64	1,733	47.0	1,118	51.3	857	53.0
	65+	143	3.9	186	8.5	334	20.7
Sex	Female	2,142	58.0	1,317	60.4	945	58.5
	Male	1,549	42.0	864	39.6	671	41.5
Race	White	3,041	82.4	1,778	81.5	1,314	81.3
	Black	397	10.8	210	9.6	168	10.4
	Hispanic	171	4.6	138	6.3	96	5.9
	Asian	67	1.8	41	1.9	26	1.6
	Other/unk.	15	0.4	14	0.6	12	0.7
Diagnosis group	A	1,578	42.8	930	42.6	724	44.8
	B	544	14.7	235	10.8	104	6.4
	C	527	14.3	301	13.8	175	10.8
	D	840	22.8	588	27.0	581	36.0
	Other/unk.	202	5.5	127	5.8	32	2.0
Most recent lung allocation score	<30	0	0.0	154	7.1	38	2.4
	30-<35	0	0.0	1,007	46.2	818	50.6
	35-<40	0	0.0	282	12.9	350	21.7
	40-<50	0	0.0	145	6.6	258	16.0
	50-100	0	0.0	62	2.8	109	6.7
	No LAS*	3,691	100.0	531	24.3	43	2.7
Blood type	A	1,343	36.4	861	39.5	639	39.5
	B	390	10.6	210	9.6	152	9.4
	AB	138	3.7	72	3.3	44	2.7
	O	1,820	49.3	1,038	47.6	781	48.3
Time on waiting list	<1 month	91	2.5	104	4.8	133	8.2
	1-<3 months	280	7.6	201	9.2	219	13.6
	3-<6 months	350	9.5	217	9.9	228	14.1
	6-<12 months	523	14.2	231	10.6	252	15.6
	1-<2 years	855	23.2	267	12.2	297	18.4
	2-<3 years	536	14.5	186	8.5	183	11.3
	3+ years	1,056	28.6	975	44.7	304	18.8
Status	Inactive	1,354	36.7	1,129	51.8	299	18.5
	Active	2,337	63.3	1,052	48.2	1,317	81.5
Transplant history	Listed for first tx	3,597	97.5	2,119	97.2	1,567	97.0
	Listed for subseq. tx	94	2.5	62	2.8	49	3.0
Multi-organ Listing	Lung-Heart	145	3.9	80	3.7	32	2.0
	Lung-Kidney	3	0.1	0	0.0	3	0.2
	Lung-Pancreas	0	0.0	2	0.1	1	0.1
	Lung-Liver	6	0.2	8	0.4	8	0.5
	Lung-Liver-Kidney	0	0.0	0	0.0	1	0.1
	Lung alone	3,537	95.8	2,091	95.9	1,571	97.2
Total		3,691	100.0	2,181	100.0	1,616	100.0

In 2007, all but 5 patients with missing LAS were listed before May 4, 2005.
 In 2012, all patients with missing LAS were listed before May 4, 2005.

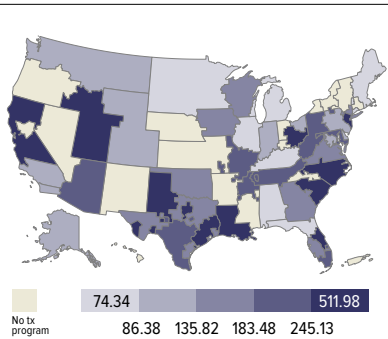
LU 1.3 Characteristics of adult patients on the lung transplant waiting list on December 31 of 2002, 2007, & 2012

Patients waiting for a transplant on December 31, 2002 and December 31, 2012, regardless of first listing date; active/inactive status is on this date, and multiple listings are not counted. Patients missing LAS in 2012 are all inactive.



LU 1.4 Lung transplant rates among active adult waiting list candidates, by age

Transplant rates are computed as the number of deceased donor transplants per 100 patient-years of active waiting time in a given year. Age is calculated on the first active listing date in a given year.



LU 1.5 Deceased donor lung transplant rates per 100 patient years on the waiting list among active adult candidates, by DSA, 2011-2012

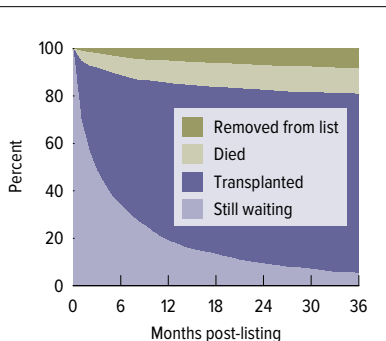
Transplant rates by DSA of the listing center, limited to those with active time on the waiting list in 2011 and 2012; deceased donor transplants only. Maximum time per listing is two years. Patients with concurrent listings in a single DSA are counted once in that DSA, and those listed in multiple DSAs are counted separately per DSA.

wait list

	2010	2011	2012
Patients at start of year	1,836	1,780	1,679
Patients added during year	2,359	2,323	2,231
Patients removed during year	2,409	2,420	2,294
Patients at end of year	1,786	1,683	1,616
Removal reason			
Deceased donor transplant	1,776	1,818	1,754
Living donor transplant	0	1	1
Patient died	338	348	303
Patient refused transplant	6	11	8
Improved, tx not needed	158	69	41
Too sick to transplant	45	81	110
Other	86	92	77

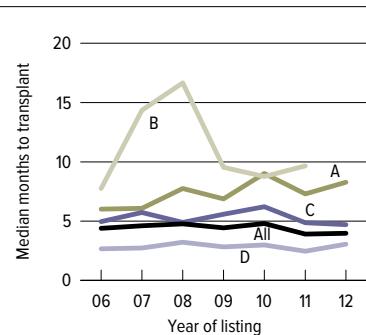
LU 1.6 Lung transplant waiting list activity among adult patients

Patients with concurrent listings at more than one center are counted once, from the time of earliest listing to the time of latest removal. Patients listed, transplanted, and re-listed are counted more than once. Patients are not considered "on the list" on the day they are removed. Thus, patient counts on January 1 may be different from patient counts on December 31 of the prior year. Patients listed for multi-organ transplants are included. Known deaths following removal for being too ill are counted as deaths.



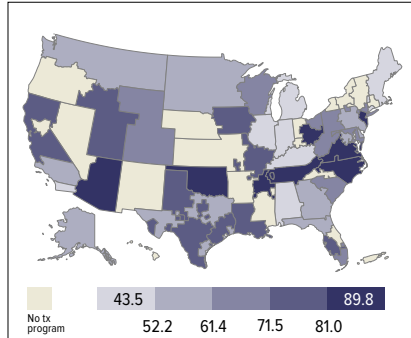
LU 1.7 Three-year outcomes for adult patients waiting for a lung transplant among new listings in 2009

Adult patients waiting for any lung transplant and first listed in 2009. Patients with concurrent listings at more than one center are counted once, from the time of the earliest listing to the time of latest removal.



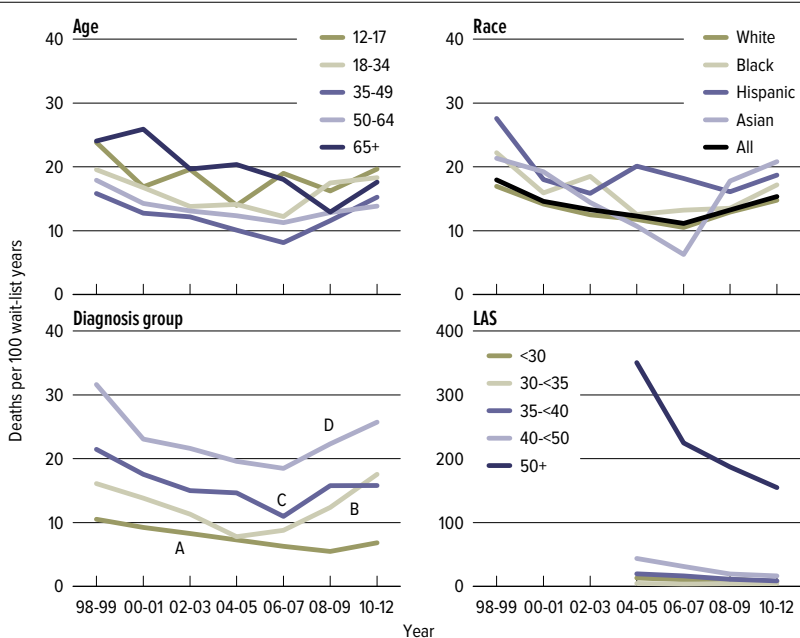
LU 1.8 Median months to lung transplant for wait-listed adult patients, by diagnosis group

Patients waiting for a transplant, with observations censored at December 31, 2012; Kaplan-Meier methods used to estimate time to transplant. If an estimate is not plotted, 50% of the cohort listed in that year had not been transplanted at the censoring date. Only the first transplant is counted.



LU 1.9 Percent of adult wait-listed patients, 2011, who received a deceased donor lung transplant within one year, by DSA

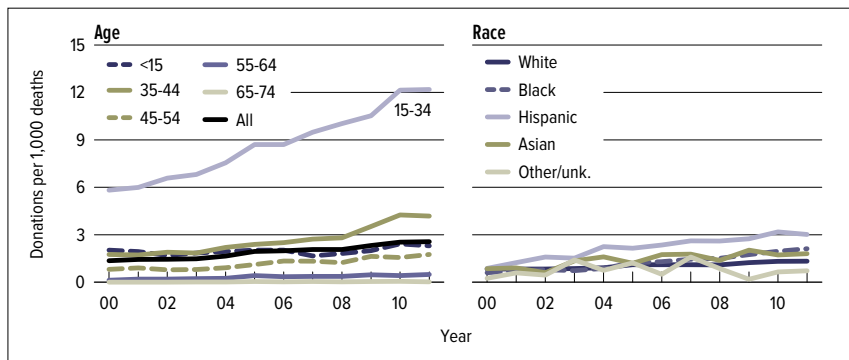
Patients with concurrent listings in a single DSA are counted once in that DSA, and those listed in multiple DSAs are counted separately per DSA.



LU 1.10 Pre-transplant mortality rates among adult patients wait-listed for a lung transplant

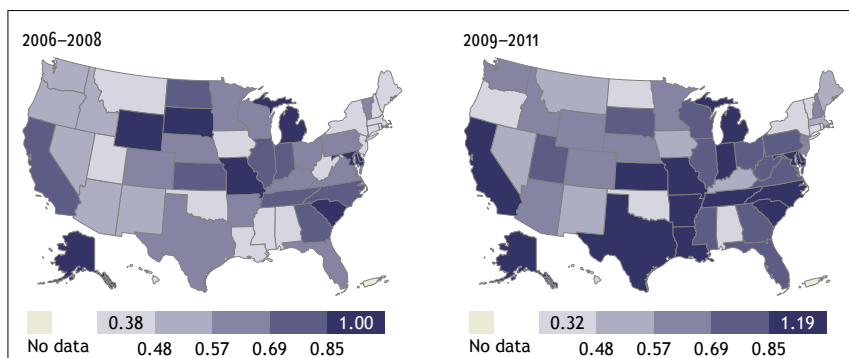
Patients waiting for a transplant. Mortality rates are computed as the number of deaths per 100 patient-years of waiting time in the given interval. For rates shown by different characteristics, waiting time is calculated as the total waiting time in the interval for patients in that group. Only deaths that occur prior to removal from the waiting list are counted. Age is calculated on the latest of listing date or January 1 of the given interval. Other patient characteristics come from the OPTN Transplant Candidate Registration form.

deceased donation



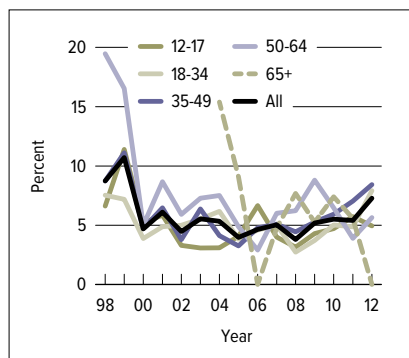
LU 2.1 Deceased donor lung donation rates

Numerator: Deceased donors age less than 75 with at least one lung recovered for transplant. Denominator: US deaths per year, age less than 75. (Death data available at <http://www.cdc.gov/nchs/products/nvsr.htm>.) Death data were available only through 2011.



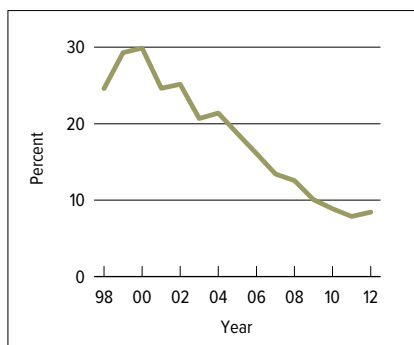
LU 2.2 Deceased donor lung donation rates (per 1,000 deaths), by state

Numerator: Deceased donors residing in the 50 states whose lung(s) was/were recovered for transplant in the given year range. Denominator: US deaths by state during the given year range. (Death data available at <http://www.cdc.gov/nchs/products/nvsr.htm>.) Rates are calculated within ranges of years for more stable estimates. Donors who donated two lungs are counted twice.



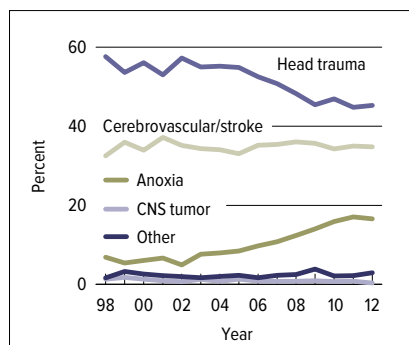
LU 2.3 Discard rates for lungs recovered for transplant

Percent of lungs discarded out of all lungs recovered for transplant. Lungs recovered as a block are counted as one organ. Lungs recovered separately are counted as two organs.



LU 2.4 Lung donors with a smoking history of 20 pack-years or more

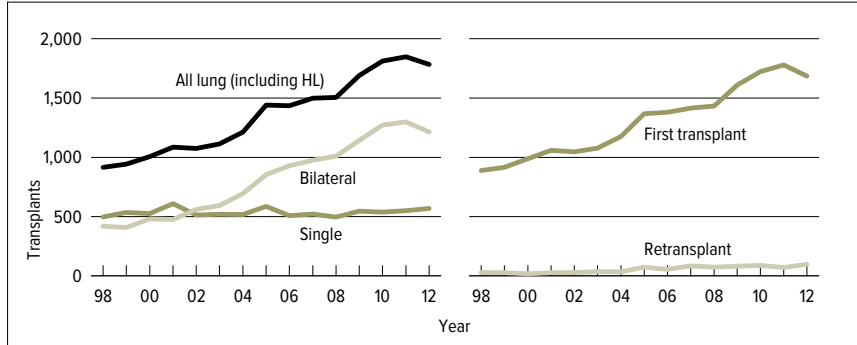
All deceased donors whose lung(s) were transplanted in the given year. Smoking history as reported to the OPTN.



LU 2.5 Cause of death among deceased lung donors

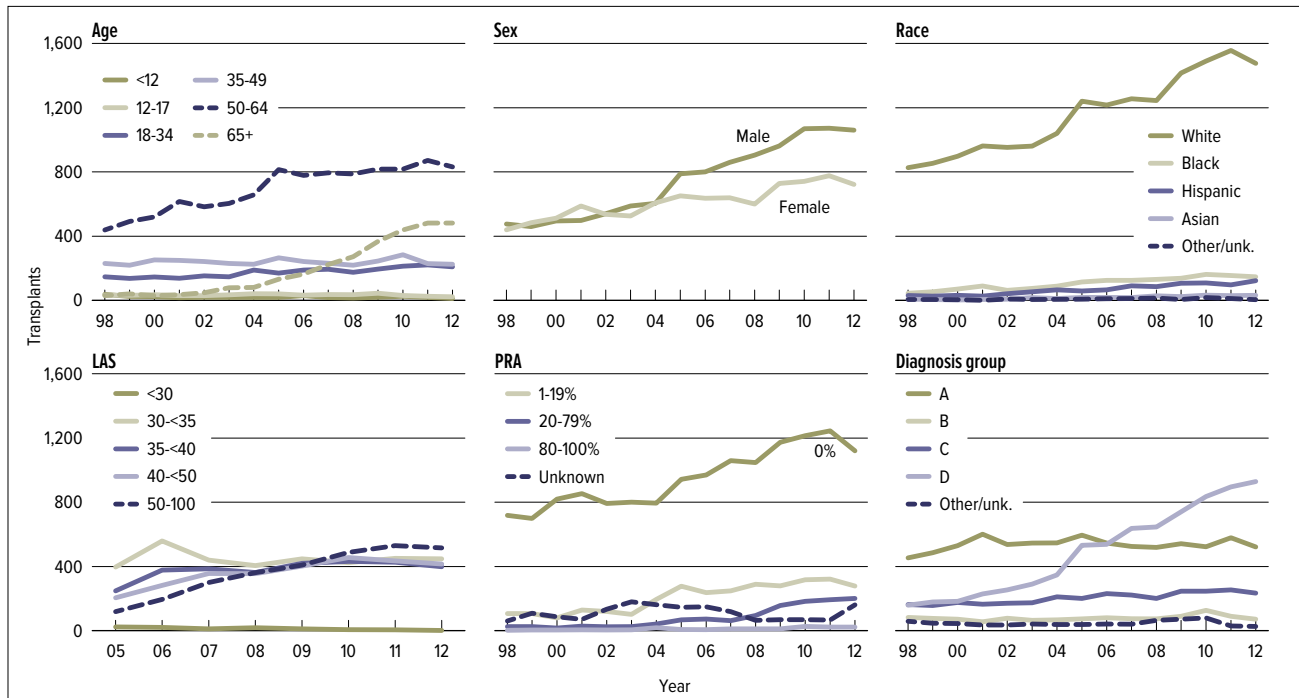
Deceased donors whose lungs were transplanted. Donors who contributed more than one lung were counted once. CNS = central nervous system.

transplant



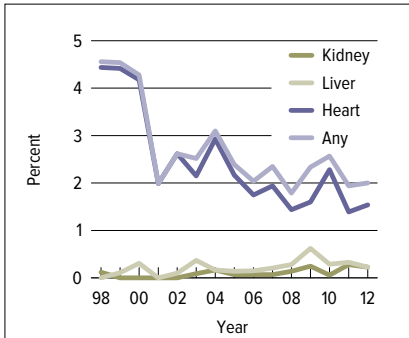
LU 3.1 Total lung transplants

Patients receiving a transplant, including multi-organ transplants and pediatric patients. Retransplants are counted.



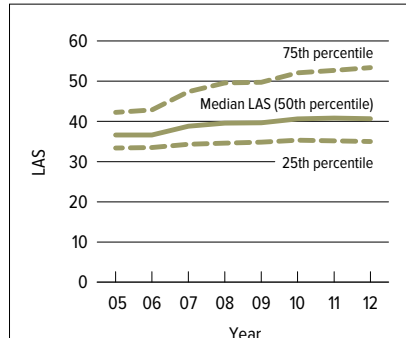
LU 3.2 Lung transplants

Patients receiving a transplant, including multi-organ transplants and pediatric patients. Retransplants are counted.



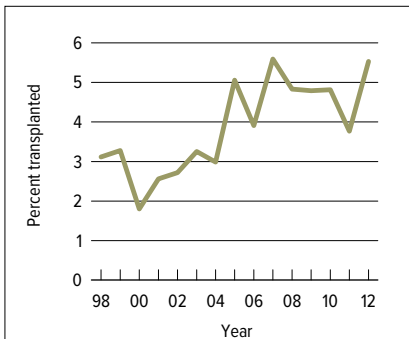
LU 3.3 Lung transplants that were part of a multi-organ transplant

All adult patients receiving a deceased donor lung transplant with at least one additional organ. A multi-organ transplant may include more than two different organs in total; if so, each non-lung organ will be considered separately. Kidney transplants include living donor transplants.



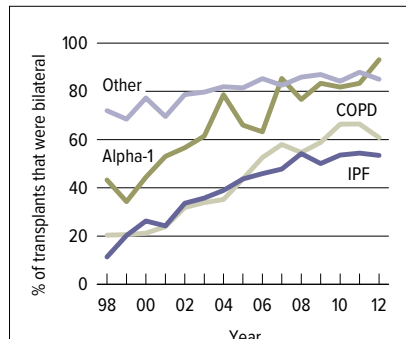
LU 3.4 Median LAS at transplant

Patients aged 12 years and older with all data required to compute LAS non-missing; last LAS prior to transplant.



LU 3.5 Retransplants among adult lung transplant recipients

Patients receiving a lung retransplant in the given year.



LU 3.6 Utilization of bilateral transplants for adult lung recipients

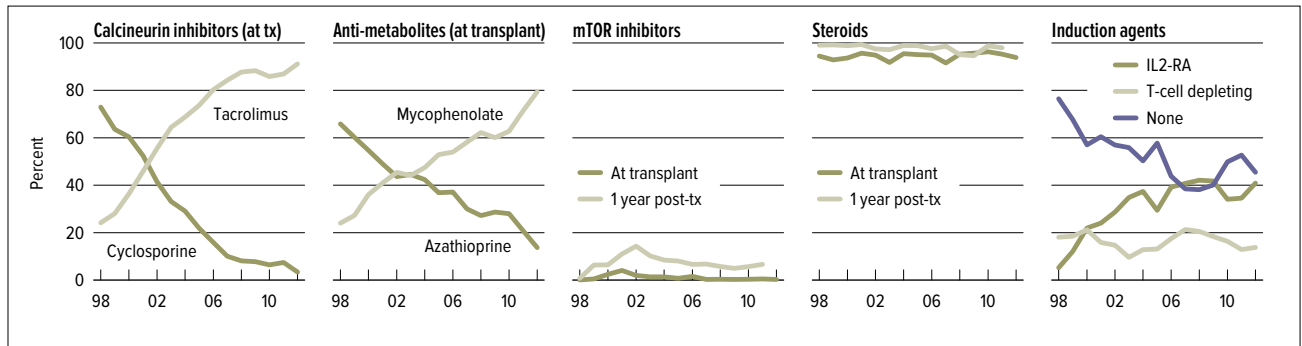
Percentage of adult lung transplants that were bilateral. Heart-lung transplants are excluded.



		2002		2007		2012				2002		2007		2012	
		N	%	N	%	N	%	N	%	N	%	N	%	N	%
Age	12-17	30	2.8	37	2.5	22	1.2	Pretransplant	Hospitalized: ICU	44	4.2	131	8.8	174	9.8
	18-34	153	14.5	194	13.1	209	11.8	medical cond.	Hosp.: not ICU	51	4.8	127	8.6	171	9.7
	35-49	242	22.9	232	15.7	226	12.8		Not hospitalized	960	91.0	1,223	82.6	1,389	78.4
	50-64	583	55.3	795	53.7	832	47.0		Unknown	0	0.0	0	0.0	37	2.1
	65+	47	4.5	223	15.1	482	27.2	On ventilator	Vent + ECMO	3	0.3	7	0.5	35	2.0
Sex	Female	528	50.0	627	42.3	714	40.3	/ECMO at tx	Vent only	22	2.1	63	4.3	80	4.5
	Male	527	50.0	854	57.7	1,057	59.7		ECMO	0	0.0	3	0.2	21	1.2
Race	White	939	89.0	1,242	83.9	1,470	83.0		Neither	1,030	97.6	1,408	95.1	1,635	92.3
	Black	62	5.9	123	8.3	145	8.2	Procedure type	Lobar	12	1.2	3	0.2	1	0.1
	Hispanic	40	3.8	89	6.0	121	6.8		Single	501	49.0	520	35.8	569	32.7
	Asian	7	0.7	16	1.1	31	1.8		Bilateral	510	49.9	930	64.0	1,172	67.3
	Other/unknown	7	0.7	11	0.7	4	0.2	Donor type	Deceased	1,043	98.9	1,478	99.8	1,770	99.9
Diagnosis group	A	537	50.9	525	35.4	522	29.5		Donation after brain death	1,042	98.8	1,469	99.2	1,749	98.8
	B	77	7.3	75	5.1	71	4.0		Donation after cardiac death	1	0.1	9	0.6	21	1.2
	C	171	16.2	222	15.0	234	13.2		Living	12	1.1	3	0.2	1	0.1
	D	254	24.1	637	43.0	929	52.5	Prior solid organ tx		28	2.7	86	5.8	100	5.6
	Other/unknown	16	2	22	1.5	15	0.8	Primary payer	Private	702	66.5	885	59.8	912	51.5
Lung allocation score (LAS)	<30	0	0	11	0.7	2	0.1		Medicare	234	22.2	429	29.0	686	38.7
	30-35	0	0	432	29.2	445	25.1		Other government	109	10.3	153	10.3	139	7.8
	35-40	0	0	382	25.8	398	22.5		Other	10	0.9	14	0.9	34	1.9
	40-45	0	0	355	24.0	413	23.3	HL vs. LU	HL	32	3.0	28	1.9	29	1.6
	50-100	0	0.0	299	20.2	513	29.0		LU	1,023	97.0	1,453	98.1	1,742	98.4
Blood type	A	462	43.8	580	39.2	688	38.8	DCD	DCD	1	0.1	9	0.6	21	1.2
	B	107	10.1	163	11.0	213	12.0		Non-DCD	1,041	98.7	1,469	99.2	1,749	98.8
	AB	41	3.9	72	4.9	69	3.9		Unknown	13.0	1.2	3.0	0.2	1.0	0.1
	O	445	42.2	666	45.0	801	45.2	Total	All patients	1055	100.0	1481	100.0	1771	100.0
Time on waiting list	<1 month	83	7.9	459	31.0	649	36.6								
	1-3 months	121	11.5	372	25.1	386	21.8								
	3-6 months	169	16.0	231	15.6	291	16.4								
	6-12 months	196	18.6	170	11.5	212	12.0								
	1-2 years	249	23.6	109	7.4	150	8.5								
	2-3 years	155	14.7	48	3.2	47	2.7								
	3+ years	77	7.3	91	6.1	36	2.0								
Unknown	5	0.5	1	0.1	0	0.0									

LU 3.7 Characteristics of adult lung transplant recipients, 2002, 2007, & 2012

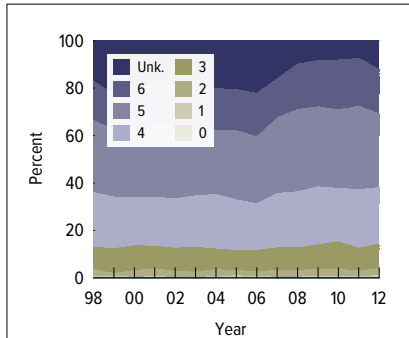
Patients receiving a transplant. Retransplants are counted. Transplants of left and right lobes for a patient on the same day are counted as one.



LU 3.8 Immunosuppression use in adult lung transplant recipients

One-year post-transplant data limited to patients with graft function one year post-transplant. Mycophenolate group includes mycophenolate mofetil and mycophenolate sodium.

donor-recipient matching



LU 4.1 Total HLA mismatches among adult lung transplant recipients

Donor and recipient antigen matching is based on the OPTN's antigen values and split equivalences policy as of 2012.

RECIPIENT	DONOR			Total
	Negative	Positive	Unknown	
Negative	15.8	24.5	0.1	40.4
Positive	18.8	35.2	0.1	54.0
Unknown	2.4	3.2	0.0	5.5
Total	36.9	62.8	0.2	100

LU 4.2 Adult lung donor-recipient cytomegalovirus (CMV) serology matching, 2008–2012

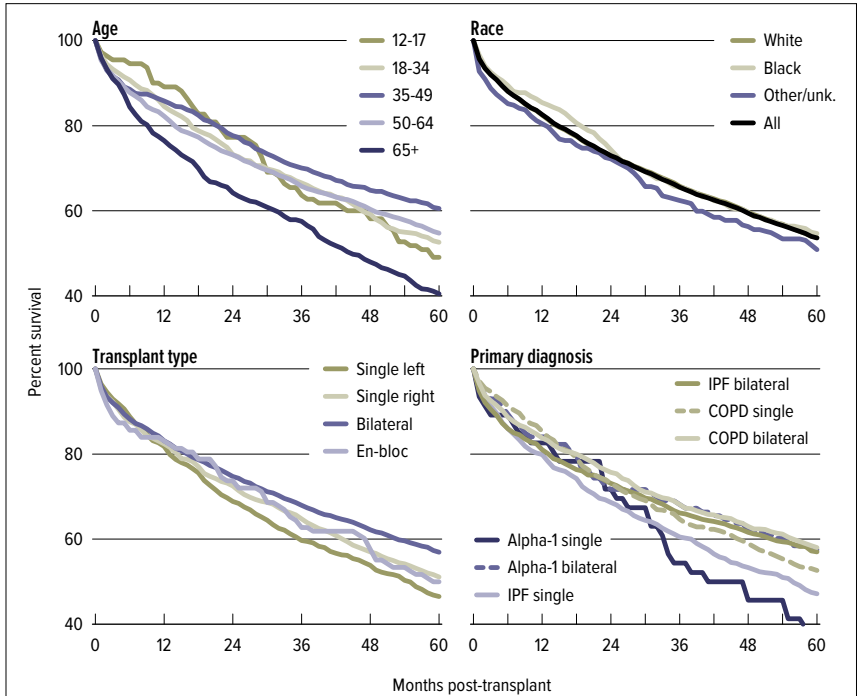
Adult transplant cohort from 2008–2012. Donor serology is reported on the OPTN donor registration forms; recipient serology is reported on the OPTN recipient registration forms. Any evidence for a positive serology is taken to indicate that the person is positive for the given serology; if all fields are unknown, not done, or pending, the person is considered to be “unknown” for that serology; otherwise, serology is assumed negative.

RECIPIENT	DONOR			Total
	Negative	Positive	Unknown	
Negative	0.6	10.3	0.0	10.9
Positive	4.4	72.2	0.2	76.8
Unknown	0.7	11.5	0.0	12.3
Total	5.8	94.0	0.2	100

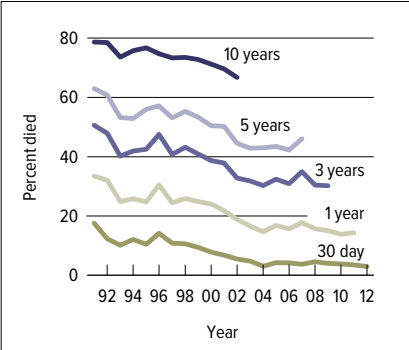
LU 4.3 Adult lung donor-recipient Epstein-Barr virus (EBV) serology matching, 2008–2012

Adult transplant cohort from 2008–2012. Donor serology is reported on the OPTN donor registration forms; recipient serology is reported on the OPTN recipient registration forms. Any evidence for a positive serology is taken to indicate that the person is positive for the given serology; if all fields are unknown, not done, or pending, the person is considered to be “unknown” for that serology; otherwise, serology is assumed negative.

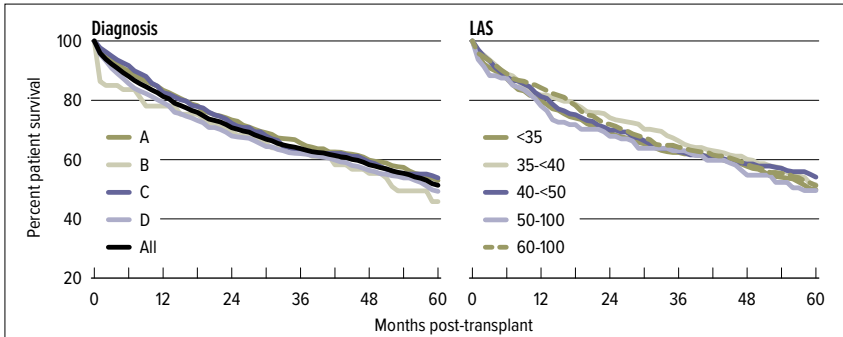
outcomes



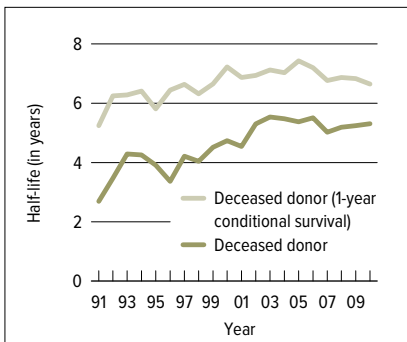
LU 5.1 Patient survival among adult lung transplant recipients, 2005–2007
 Percent patient survival using unadjusted Kaplan-Meier methods. For patients with more than one transplant during the period, only their first transplant is considered.



LU 5.2 Patient death among adult lung transplant recipients
 Cox proportional hazards models reporting probability, adjusting for age, sex, and race.

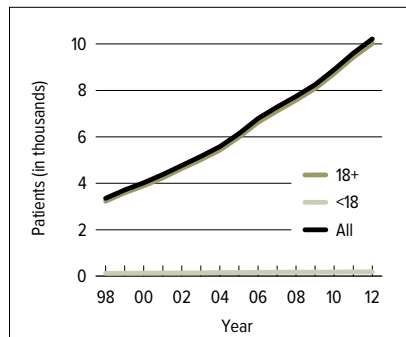


LU 5.3 Patient survival among adult lung transplant recipients transplanted in 2007
Recipient survival estimated using unadjusted Kaplan-Meier methods.



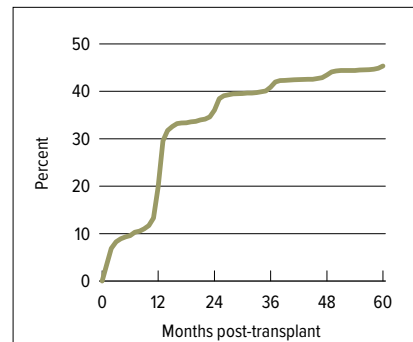
LU 5.4 Half-lives for adult lung transplant recipients

The half-life for a transplant cohort (e.g. 2009 lung transplants) is the time point in follow-up at which 50% of the transplanted grafts have failed. A conditional half-life for a transplant cohort is the same calculation but limited to those who survive with function at least 1 year post-transplant.



LU 5.5 Recipients alive & with a functioning lung transplant on June 30 of the year

Txs before June 30 of the year that are still functioning. Pts are assumed alive with function unless a death or graft failure is recorded. A recipient can experience a graft failure and drop from the cohort, then be retransplanted and re-enter the cohort. Age cut is based on age at tx.



LU 5.6 Incidence of first acute rejection among adult patients receiving a lung transplant in 2006–2010

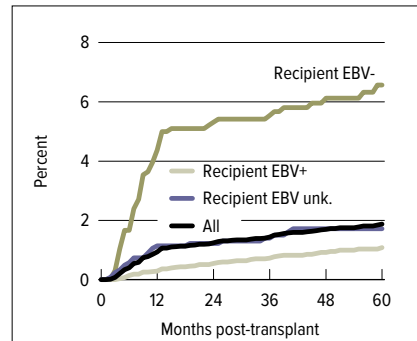
Acute rejection defined as a record of acute or hyperacute rejection, or a record of an anti-rejection drug being administered on either the Transplant Recipient Registration form or the Transplant Recipient Follow-up form. Only the first rejection event is counted. Cumulative incidence, defined as the probability of acute rejection at any time prior to the given time, is estimated using Kaplan-Meier competing risk methods.

outcomes

	Level	One-year events, 2009–11 tx		Five-year events, 2005–07 tx	
		N	%	N	%
Bronchiolitis	Grade 3	36	0.8	133	6.2
Obliterans syndrome (BOS)	Grade 2	33	0.8	110	5.1
	Grade 1	81	1.9	229	10.6
	Grade OP	97	2.2	236	10.9
	Grade unk.	97	2.2	219	10.2
	No	3,886	88.8	1,225	56.8
	Unk.	148	3.4	4	0.2
Renal dysfunction	Yes	754	17.2	1,074	49.8
	No	3,614	82.5	1,082	50.2
	Unk.	10	0.2	0	0.0
Creatinine > 2.5 mg/dl	Yes	183	4.2	287	13.3
	No	569	13.0	782	36.3
	Unk.	3,626	82.8	1,087	50.4
Chronic Dialysis	Yes	46	1.1	52	2.4
	No	707	16.1	1,021	47.4
	Unk.	3,625	82.8	1,083	50.2
Renal tx after thoracic tx	Yes	3	0.1	13	0.6
	No	751	17.2	1,061	49.2
	Unk.	3,624	82.8	1,082	50.2
Hypertension, drug-treated	Yes	1,647	37.6	1,438	66.7
	No	1,687	38.5	463	21.5
	Unk.	1,044	23.8	255	11.8
Diabetes	Yes	744	17.0	917	42.5
	No	3,621	82.7	1,239	57.5
	Unk.	13	0.3	0	0.0
Malignancy	Yes	140	3.2	395	18.3
	No	4,212	96.2	1,761	81.7
	Unk.	26	0.6	0	0.0
Drug-treated hyperlipidemia	Yes	1,002	22.9	1,161	53.8
	No	2,298	52.5	834	38.7
	Unk.	1,078	24.6	161	7.5
Re-hospitalization	Yes	2,244	51.3	1,763	81.8
	No	2,053	46.9	371	17.2
	Unk.	81	1.9	22	1.0
Functional status	No assistance needed	3,679	84.0	1,864	86.5
	Some assistance needed	436	10.0	151	7.0
	Total assistance needed	78	1.8	30	1.4
	Unknown	185	4.2	111	5.1
All		4,378	100.0	2,156	100.0

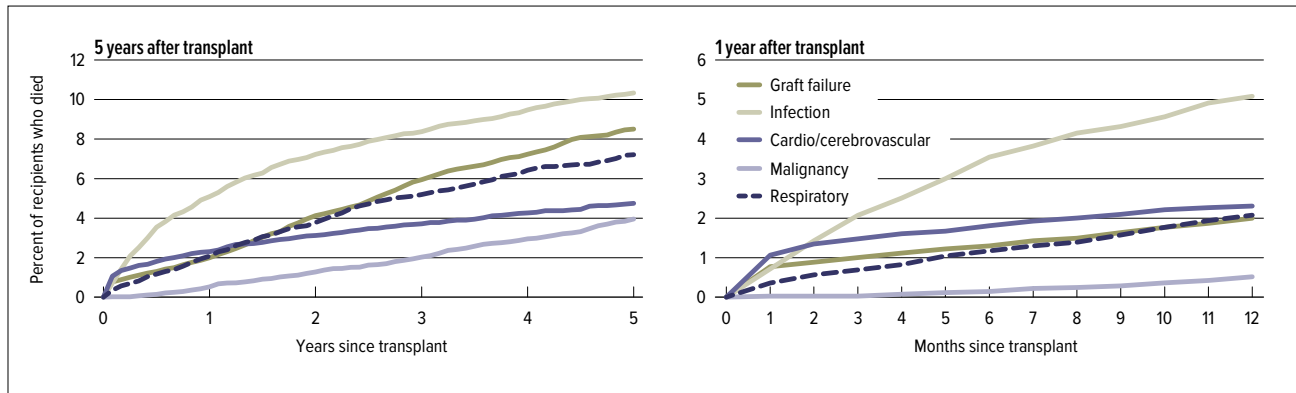
LU 5.7 Post-transplant events among adult lung transplant recipients

Post-transplant morbidities are recorded on the Transplant Recipient Follow-up forms and are included in the table if they are reported anytime on or before the 1-year and 5-year follow-ups. One-year events are reported for survivors transplanted 2009–2011; five-year events are reported for survivors transplanted 2005–2007. Patients with more than one transplant are counted separately per transplant. For BOS, the most severe complication recorded for each transplant is counted.



LU 5.8 Incidence of PTLD among adult patients receiving a lung transplant in 2006–2010, by recipient Epstein-Barr virus (EBV) status at transplant

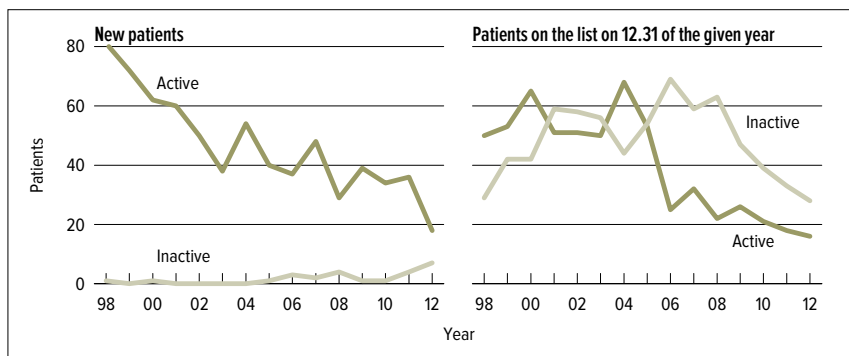
The cumulative incidence is estimated using Kaplan-Meier competing risks methods. PTLD is identified as either a reported complication or cause of death on the Transplant Recipient Follow-up form or on the Post-transplant Malignancy form as polymorphic PTLD, monomorphic PTLD, or Hodgkin's Disease. Only the earliest date of PTLD diagnosis is considered.



LU 5.9 Cumulative incidence of death by cause among adult lung recipients transplanted 2006–2010

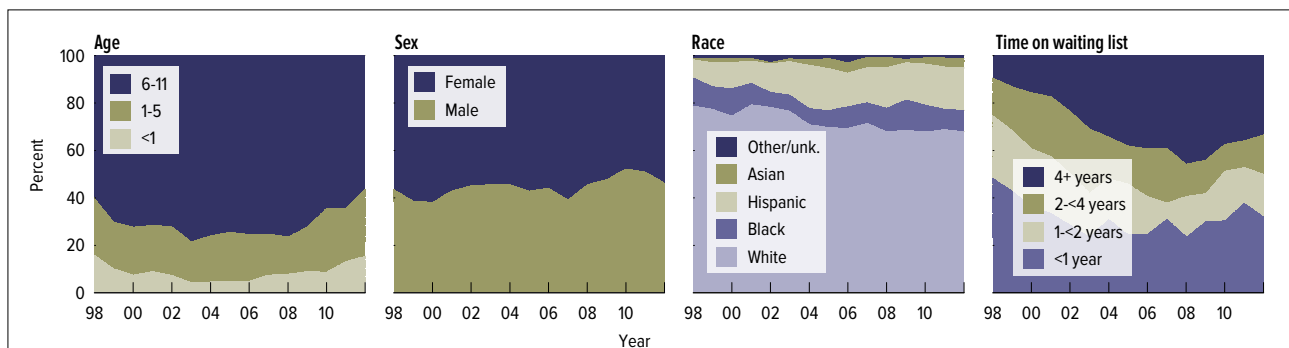
Primary cause of death is as reported to the OPTN from the Transplant Follow-up form. Other causes of death include hemorrhage, trauma, non-compliance, unspecified other, unknown, etc. Cumulative incidence is estimated using Kaplan-Meier competing risk methods.

pediatric transplant



LU 6.1 Pediatric patients waiting for a lung transplant

Patients waiting for a transplant. A "new patient" is one who first joins the list during the given year, without having listed in a previous year. However, if a patient has previously been on the list, has been removed for a transplant, and has relisted since that transplant, the patient is considered a "new patient." Patients concurrently listed at multiple centers are counted only once. Those with concurrent listings and active at any program are considered active; those inactive at all programs at which they are listed are considered inactive.



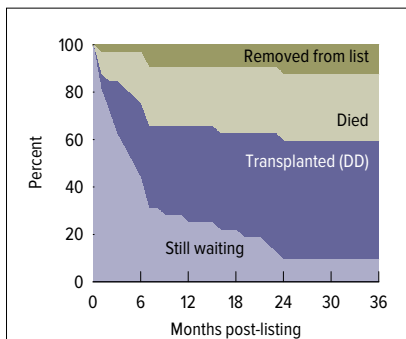
LU 6.2 Distribution of pediatric patients waiting for a lung transplant

Patients waiting for a transplant any time in the given year. Age determined on the latest of listing date or January 1 of the given year. Concurrently listed patients are counted once.

	2010	2011	2012
Patients at start of year	80	66	53
Patients added during year	35	40	25
Patients removed during year	49	53	34
Patients at end of year	66	53	44
Removal reason			
Received a transplant	26	20	16
Patient died	12	13	11
improved, tx not needed	10	7	6
Too sick to transplant	0	4	0
Other	1	9	1

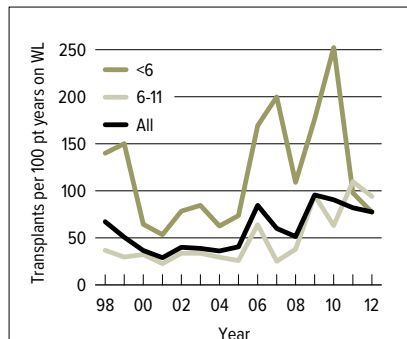
LU 6.3 Lung transplant waiting list activity among pediatric patients

Patients with concurrent listings at more than one center are counted once, from the time of earliest listing to the time of latest removal. Patients listed, transplanted, and re-listed are counted more than once. Patients are not considered "on the list" on the day they are removed. Thus, patient counts on January 1 may be different from patient counts on December 31 of the prior year. Patients listed for multi-organ transplants are included.



LU 6.4 Three-year outcomes for pediatric patients waiting for a lung transplant among new listings in 2009

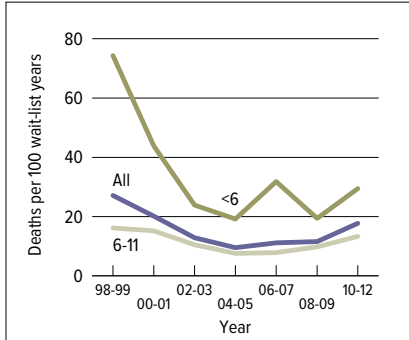
Patients waiting for a transplant and first listed in 2009. Patients with concurrent listings at more than one center are counted once, from the time of the earliest listing to the time of latest removal.



LU 6.5 Lung transplant rates among active pediatric waiting list candidates, by age

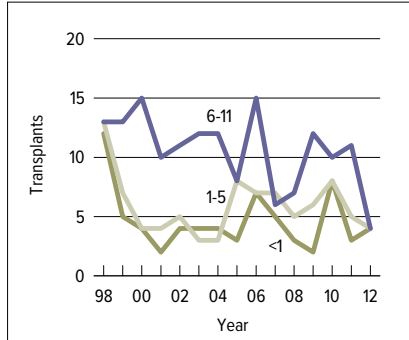
Transplant rates are computed as the number of deceased donor transplants per 100 patient-years of active waiting time in the given year. Age is calculated on the first active listing date in a given year.

pediatric transplant



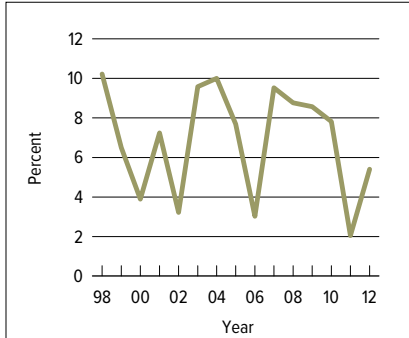
LU 6.6 Pre-transplant mortality rates among pediatric patients wait-listed for a lung transplant, by age

Patients waiting for a transplant. Mortality rates are computed as the number of deaths per 100 patient-years of waiting time in the given interval. Waiting time is calculated as the total waiting time per age group in the interval. Only deaths that occur prior to removal from the waiting list are counted. Age is calculated on the latest of listing date or January 1 of the given period.



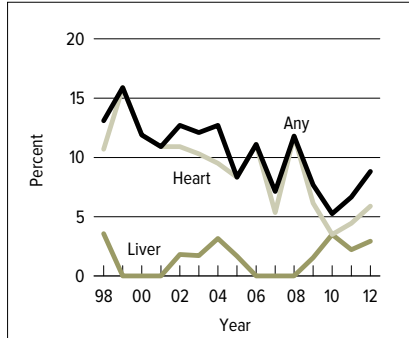
LU 6.7 Pediatric lung transplants, by age

Patients receiving a lung or heart-lung transplant.



LU 6.8 Retransplants among pediatric lung transplant recipients

Includes patients transplanted after age 17, but listed at age 17 or younger. Retransplanted patients include only those with a prior transplant of the same type. Includes patients transplanted after age 12, but listed at age 12 or younger. Retransplanted patients include only those with a prior transplant of the same type.



LU 6.9 Pediatric lung transplants that were part of a multi-organ transplant

Patients receiving a deceased donor lung transplant with at least one additional organ. A multi-organ transplant may include more than two different organs in total; if so, each non-lung organ will be considered separately.

		2000-02		2010-12	
	Level	N	%	N	%
Age	<1	10	16.9	15	26.3
	1-5	13	22.0	17	29.8
	6-11	36	61.0	25	43.9
Sex	Female	37	62.7	30	52.6
	Male	22	37.3	27	47.4
Race	White	42	71.2	36	63.2
	Black	6	10.2	7	12.3
	Hispanic	6	10.2	12	21.1
	Asian	3	5.1	2	3.5
	Other/unk.	2	3.4	0	0.0
	Primary diagnosis	Cystic fib.	18	30.5	11
Pulm. HTN		14	23.7	9	15.8
Pulm. fibrosis		4	6.8	12	21.1
Other vasc.		2	3.4	4	7.0
All others		21	35.6	21	36.8
Transplant number	First	57	96.6	54	94.7
	Retx	2	3.4	3	5.3
Blood type	A	19	32.2	23	40.4
	B	8	13.6	9	15.8
	AB	2	3.4	4	7.0
	O	30	50.8	21	36.8
Time on waiting list	<1 mo.	11	18.6	12	21.1
	1-<3 mo.	11	18.6	21	36.8
	3-<6 mo.	6	10.2	11	19.3
	6-<12 mo.	13	22.0	7	12.3
	1-<2 yrs	12	20.3	4	7.0
	2+ yrs	4	6.8	2	3.5
	Unknown	2	3.4	0	0.0
Pretx medical condition	Hosp: ICU	17	28.8	19	33.3
	Hosp: not ICU	6	10.2	8	14.0
Pt on vent. imm.ly pre-tx	Not hosp.	36	61.0	30	52.6
	No	48	81.4	35	61.4
Procedure type	Yes	11	18.6	22	38.6
	Bilat. seq.	41	69.5	50	87.7
	Bilat. en-bloc	7	11.9	5	8.8
	Lobe	3	5.1	0	0.0
	Heart-lung	8	13.6	2	3.5
Donor type	Deceased	56	94.9	57	100.0
	Living	3	5.1	0	0.0
Primary payer	Private	37	62.7	22	38.6
	Medicaid	18	30.5	27	47.4
	Other public	3	5.1	3	5.3
	Unknown	1	1.7	5	8.8
HL vs. LU	LU	51	86.4	55	96.5
	HL	8	13.6	2	3.5
ECMO	not ECMO	56	94.9	55	96.5
	ECMO	3	5.1	2	3.5
All patients		59	100.0	57	100.0

LU 6.10 Characteristics of pediatric lung transplant recipients, 2000-2002 & 2010-2012

Patients receiving a transplant. Retransplants are counted.

RECIPIENT	DONOR			Total
	Negative	Positive	Unknown	
Negative	25.0	33.3	1.2	59.5
Positive	13.1	26.2	0.0	39.3
Unknown	1.2	0.0	0.0	1.2
Total	39.3	59.5	1.2	100

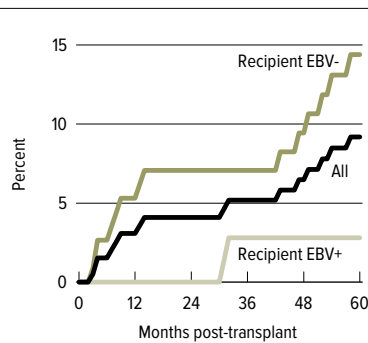
LU 6.11 Lung donor-recipient Epstein-Barr virus (EBV) serology matching for pediatric transplant recipients, 2008–2012

Pediatric transplant cohort from 2008–2012. Donor EBV serology is reported on the OPTN donor registration forms; recipient EBV serology is reported on the OPTN recipient registration forms. Any evidence for a positive serology is taken to indicate that the person is positive for EBV; if all fields are unknown, not done, or pending, the person is considered to be “unknown” for that serology; otherwise, serology is assumed negative.

RECIPIENT	DONOR			Total
	Negative	Positive	Unknown	
Negative	27.4	35.7	0.0	63.1
Positive	9.5	23.8	2.4	35.7
Unknown	0.0	1.2	0.0	1.2
Total	36.9	60.7	2.4	100

LU 6.12 Lung donor-recipient cytomegalovirus (CMV) serology matching for pediatric transplant recipients, 2008–2012

Pediatric transplant cohort from 2008–2012. Donor CMV serology is reported on the OPTN donor registration forms; recipient CMV serology is reported on the OPTN recipient registration forms. Any evidence for a positive serology is taken to indicate that the person is positive for CMV; if all fields are unknown, not done, or pending, the person is considered to be “unknown” for that serology; otherwise, serology is assumed negative.



LU 6.13 Incidence of PTLD among pediatric patients receiving a lung transplant, 2000–2010, by recipient Epstein-Barr virus (EBV) status at transplant

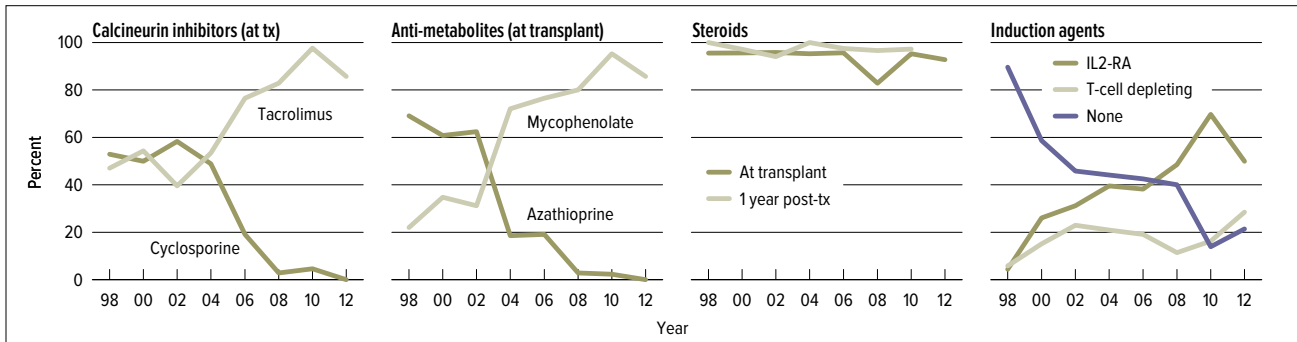
The cumulative incidence, is estimated using Kaplan-Meier competing risks methods. PTLD is identified as either a reported complication or cause of death on the Transplant Recipient Follow-up form or on the Post-transplant Malignancy form as polymorphic PTLD, monomorphic PTLD, or Hodgkin's Disease. Only the earliest date of PTLD diagnosis is considered.

Level	One-year events, 2008–11 tx		Five-year events, 2004–07 tx		
	N	%	N	%	
Bronchiolitis	Grade 3	1	1.6	0	0.0
	Obliterans	0	0.0	1	2.2
	Grade 1	0	0.0	1	2.2
	Grade OP (BOS)	0	0.0	1	2.2
	Grade unk.	1	1.6	5	11.1
Renal dysfunction	No	57	90.5	37	82.2
	Unk.	4	6.3	0	0.0
	Yes	1	1.6	8	17.8
Hypertension, drug-treated	No	62	98.4	37	82.2
	Unk.	0	0.0	0	0.0
	Yes	16	25.4	26	57.8
Diabetes	No	44	69.8	17	37.8
	Unk.	3	4.8	2	4.4
	Yes	1	1.6	5	11.1
Malignancy	No	62	98.4	40	88.9
	Unk.	0	0.0	0	0.0
	Yes	0	0.0	2	4.4
Drug-treated hyperlipidemia	No	63	100.0	43	95.6
	Unk.	0	0.0	0	0.0
	Yes	2	3.2	9	20.0
Re-hosp.	No	58	92.1	35	77.8
	Unk.	3	4.8	1	2.2
	Yes	33	52.4	39	86.7
Functional status	No	30	47.6	6	13.3
	Unk.	0	0.0	0	0.0
	Min. active	4	6.3	3	6.7
	Fully active	56	88.9	40	88.9
Total	Bedbound	1	1.6	0	0.0
	Unknown	2	3.2	2	4.4
	Total	63	100.0	45	100.0

LU 6.14 Post-transplant events among pediatric lung transplant recipients

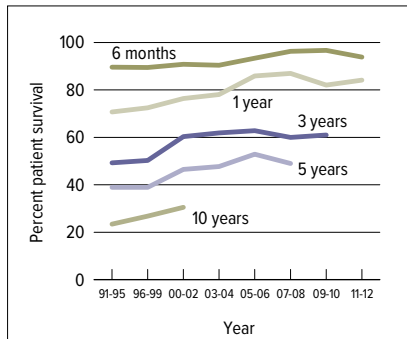
One-year events are reported for patients transplanted 2008–2011; five-year events are reported for those transplanted 2004–2007. Patients with more than one transplant are counted separately per transplant. Patients who did not survive the transplant hospitalization are excluded. For BOS, the most severe complication recorded for each transplant is counted.

pediatric transplant



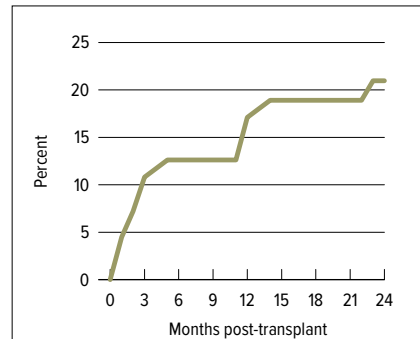
LU 6.15 Immunosuppression use in pediatric lung transplant recipients

One-year post-transplant data limited to patients alive with graft function one year post-transplant. Mycophenolate group includes mycophenolate mofetil and mycophenolate sodium.



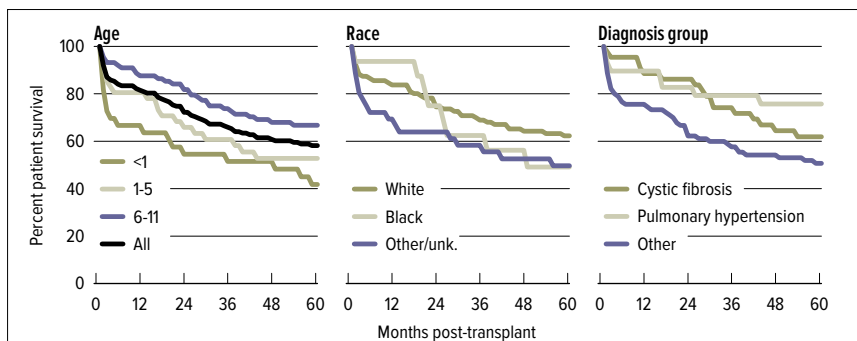
LU 6.16 Patient survival among pediatric lung transplant recipients

Estimates computed with Cox proportional hazards model, adjusted for age, sex, and race.



LU 6.17 Incidence of first acute rejection among pediatric patients receiving a lung transplant in 2006–2011

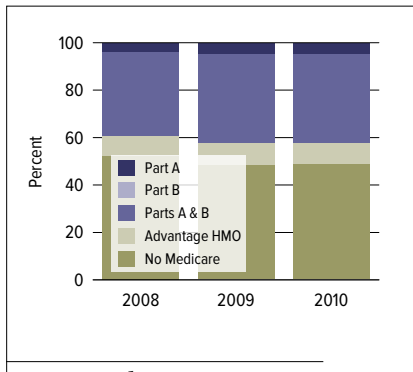
Acute rejection defined as a record of acute or hyperacute rejection, or a record of an anti-rejection drug being administered on either the Transplant Recipient Registration form or the Transplant Recipient Follow-up form. Only the first rejection event is counted. Cumulative incidence, defined as the probability of acute rejection at any time prior to the given time, is estimated using Kaplan-Meier competing risk methods.



LU 6.18 Survival among pediatric lung transplant recipients transplanted in 2000–2007

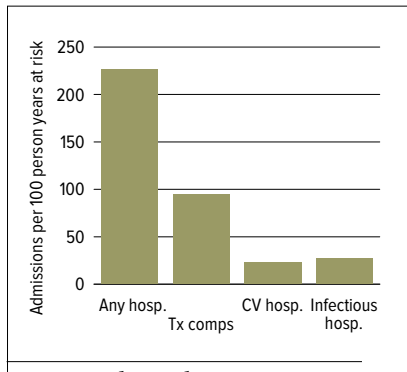
Recipient survival estimated using unadjusted Kaplan-Meier methods.

Medicare data



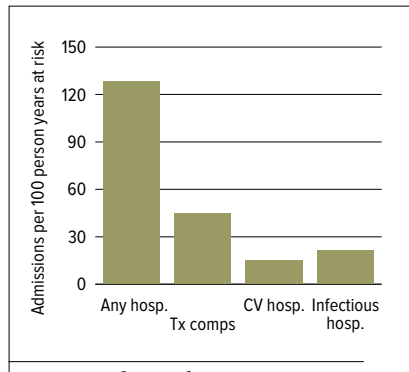
LU 7.1 Medicare coverage among lung transplant recipients

Coverage at the time of transplant as identified by the Medicare Beneficiary Annual Summary supplied by CMS.



LU 7.2 Rehospitization rates among lung transplant recipients in the first post-transplant year

Transplant recipients, 2008, with Medicare as the primary payer at transplant. Rehospitizations and reasons for rehospitization determined from Medicare claims. First year rates are based on rehospitizations occurring from initial discharge to one year later.



LU 7.3 Rehospitization rates among lung transplant recipients in the second post-transplant year

Transplant recipients, 2008, with Medicare as the primary payer at transplant. Rehospitizations and reasons for rehospitization determined from Medicare claims. Second year rates are based on hospitalizations occurring from initial discharge+1 year to initial discharge+2 years.

Year 1 Cause of hospitalization	Percent of hospitalizations	Year 2 Cause of hospitalization	Percent of hospitalizations
Transplant complication	43.7	Transplant complication	36.0
Gastro-intestinal	10.4	Other	8.6
Other	6.0	Respiratory infection	7.5
Respiratory	5.2	Other infection	6.5
Other infection	5.0	Gastro-intestinal	6.3
Respiratory infection	4.2	Genito-urinary and breast	4.1
Genito-urinary and breast	4.2	Circulatory system	4.1
Conduction disorders & dysrhythmias	3.4	Respiratory	3.7
Immune and hematologic	2.6	Bacteremia, viremia & septicemia	2.6
CHF, fluid overload and cardiomyopathy	1.9	metabolic, endocrine, nutritional	2.6

LU 7.4 Top ten causes of rehospitization among lung recipients transplanted in 2008 with Medicare primary coverage

Transplant recipients, 2008, with Medicare as the primary payer at transplant. Reasons for rehospitization determined from Medicare claims, denominator for percentages includes only those re-hospitalized.

Medicare data

		# patients	Total costs		PPPY costs	
			Part A	Part B	Part A	Part B
	All patients	885	162,982,412	22,723,606	207,013	28,862
Age	18-34	73	15,242,024	2,123,656	230,681	32,141
	35-49	99	19,809,798	2,815,768	235,018	33,406
	50-64	345	61,346,851	8,475,409	197,793	27,326
	65+	368	66,583,738	9,308,774	203,753	28,486
Sex	Male	536	94,170,722	13,254,563	199,624	28,097
	Female	349	68,811,690	9,469,043	218,057	30,006
Race	White	753	136,868,978	19,297,569	202,295	28,522
	Black	78	14,784,870	2,098,958	230,382	32,707
	Hispanic	40	8,107,618	978,864	241,062	29,104
	Asian/Pac. Isl.	*	*	*	*	*
	Other/unk.	*	*	*	*	*
Primary diagnosis	A: obstructive/COPD	380	66,349,558	9,257,207	194,297	27,109
	B: pulm vasc/iPAH	41	8,327,867	1,280,021	261,028	40,121
	C: cystic fibrosis	86	16,816,251	2,612,529	212,437	33,004
	D: restrictive/IPF	352	67,334,802	8,994,053	216,455	28,912
	E: other/unk. (HL)	26	4,153,934	579,795	175,424	24,485

LU 7.5 Total and per-person per-year (PPPY) Medicare costs (\$) among lung transplant recipients in the first post-transplant year

Costs among recipients transplanted in 2008 and 2009 who had Medicare as the primary payer at the time of transplant. First year costs include the transplant hospitalization. Costs incurred after a transplant failure are excluded. Values for cells with 9 or fewer patients are suppressed.

		# patients	Total costs		PPPY costs	
			Part A	Part B	Part A	Part B
	All patients	324	11,407,184	4,003,364	38,253	13,425
Age	18-34	30	1,489,390	467,791	55,040	17,287
	35-49	31	1,057,578	386,592	38,952	14,239
	50-64	135	4,607,606	1,590,841	36,068	12,453
	65+	128	4,252,610	1,558,139	36,584	13,404
Sex	Male	200	6,060,637	2,346,428	32,902	12,738
	Female	124	5,346,547	1,656,936	46,898	14,534
Race	White	275	10,168,438	3,459,637	40,494	13,777
	Black	29	759,355	314,181	28,087	11,621
	Hispanic	13	413,574	180,127	31,726	13,818
	Asian/Pac. Isl.	*	*	*	*	*
	Other/unk.	*	*	*	*	*
Primary diagnosis	A: obstructive/COPD	152	5,526,159	1,737,600	39,306	12,359
	B: pulm vasc/iPAH	13	378,278	164,539	31,069	13,514
	C: cystic fibrosis	31	1,586,942	495,456	57,124	17,834
	D: restrictive/IPF	117	3,830,954	1,518,090	35,929	14,238
	E: other/unk. (HL)	11	84,851	87,679	7,693	7,949

LU 7.6 Total and per-person per-year (PPPY) Medicare costs (\$) among lung transplant recipients in the second post-transplant year

Costs among recipients transplanted in 2008 who had Medicare as the primary payer at the time of transplant. The second post-transplant year runs from 366 to 730 days after transplant. Costs incurred after a transplant failure are excluded. Values for cells with 9 or fewer patients are suppressed.

Medicare data

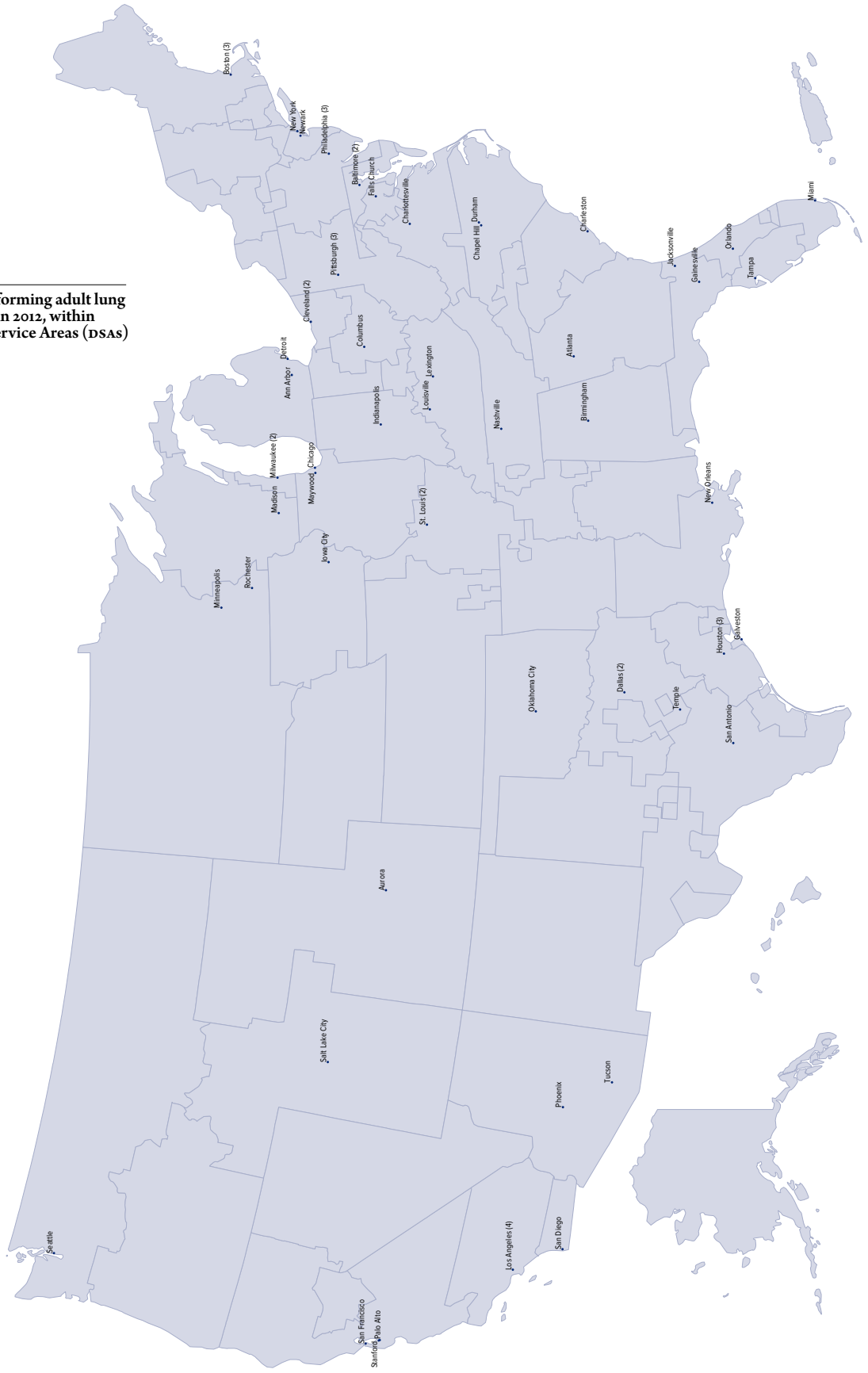
Total costs		2008 total costs			2009 total costs			2010 total costs		
		# patients	Part A	Part B	# patients	Part A	Part B	# patients	Part A	Part B
All patients		4,693	145,171,793	33,458,212	5,197	174,454,896	43,047,009	5,617	186,471,645	46,234,769
Age	0-11	*	*	*	11	160,342	59,002	*	*	*
	12-17	10	360,876	96,504	16	758,434	83,698	17	133,818	59,964
	18-34	449	14,998,736	3,150,111	479	17,585,257	4,484,646	508	16,607,033	4,068,712
	35-49	965	23,949,182	6,247,577	997	28,010,650	7,522,287	1,027	28,343,631	7,601,674
	50-64	2,622	70,008,960	17,252,230	2,865	79,030,205	21,344,853	2,980	82,473,712	22,235,390
	65+	639	35,690,123	6,666,645	829	48,910,007	9,552,522	1,076	58,804,909	12,221,164
Sex	Male	2,529	84,513,219	18,736,353	2,858	97,959,723	24,101,142	3,120	105,175,762	26,257,101
	Female	2,164	60,658,575	14,721,859	2,339	76,495,174	18,945,867	2,497	81,295,883	19,977,668
Race	White	4,124	124,219,330	29,088,764	4,539	149,059,229	37,548,064	4,894	158,579,766	40,297,524
	Black	367	13,989,953	2,836,839	413	15,840,390	3,256,190	435	15,970,472	3,344,090
	Hispanic	141	4,725,583	1,074,693	181	7,006,529	1,642,190	209	8,921,331	1,940,496
	Asian/Pacific Islander	38	1,608,477	297,079	40	1,845,714	321,772	49	1,687,516	358,942
	Other/unk.	23	628,450	160,837	24	703,035	278,795	30	1,312,560	293,717
Primary diagnosis	A: obstructive/COPD	2,436	70,934,523	17,406,676	2,544	77,653,967	20,785,395	2,579	78,104,935	21,302,431
	B: pulm vasc/iPAH	274	7,369,342	1,799,178	295	9,839,667	2,440,269	331	13,272,912	2,951,984
	C: cystic fibrosis	492	15,284,124	3,501,858	533	18,516,242	4,937,632	590	18,458,000	5,085,290
	D: restrictive/IPF	1,401	48,961,935	10,196,576	1,702	64,675,281	13,989,699	1,974	73,123,442	15,914,706
	E: other/unk.	90	2,621,869	553,923	123	3,769,740	894,014	143	3,512,356	980,359

Per person per year costs		2008 PPPY costs			2009 PPPY costs			2010 PPPY costs		
		# patients	Part A	Part B	# patients	Part A	Part B	# patients	Part A	Part B
All patients		4,693	35,382	8,155	5,197	38,855	9,588	5,617	38,313	9,500
Age	0-11	*	*	*	11	16,375	6,026	*	*	*
	12-17	10	36,088	9,650	16	47,532	5,246	17	9,585	4,295
	18-34	449	37,269	7,827	479	41,022	10,462	508	37,474	9,181
	35-49	965	27,413	7,151	997	31,483	8,455	1,027	30,224	8,106
	50-64	2,622	30,020	7,398	2,865	31,205	8,428	2,980	31,216	8,416
	65+	639	74,820	13,976	829	79,771	15,580	1,076	71,619	14,884
Sex	Male	2,529	38,507	8,537	2,858	40,095	9,865	3,120	39,481	9,857
	Female	2,164	31,788	7,715	2,339	37,375	9,257	2,497	36,901	9,068
Race	White	4,124	34,377	8,050	4,539	38,003	9,573	4,894	37,327	9,485
	Black	367	44,525	9,029	413	43,943	9,033	435	42,632	8,927
	Hispanic	141	38,310	8,712	181	46,418	10,879	209	50,181	10,915
	Asian/Pacific Islander	38	48,953	9,041	40	54,255	9,459	49	41,275	8,779
	Other/unk.	23	32,901	8,420	24	31,774	12,600	30	51,888	11,611
Primary diagnosis	A: obstructive/COPD	2,436	33,418	8,201	2,544	35,119	9,400	2,579	34,464	9,400
	B: pulm vasc/iPAH	274	29,700	7,251	295	37,740	9,360	331	47,595	10,585
	C: cystic fibrosis	492	34,471	7,898	533	39,056	10,415	590	35,819	9,868
	D: restrictive/IPF	1,401	40,497	8,434	1,702	44,981	9,730	1,974	43,563	9,481
	E: other/unk.	90	32,841	6,938	123	35,544	8,430	143	27,443	7,660

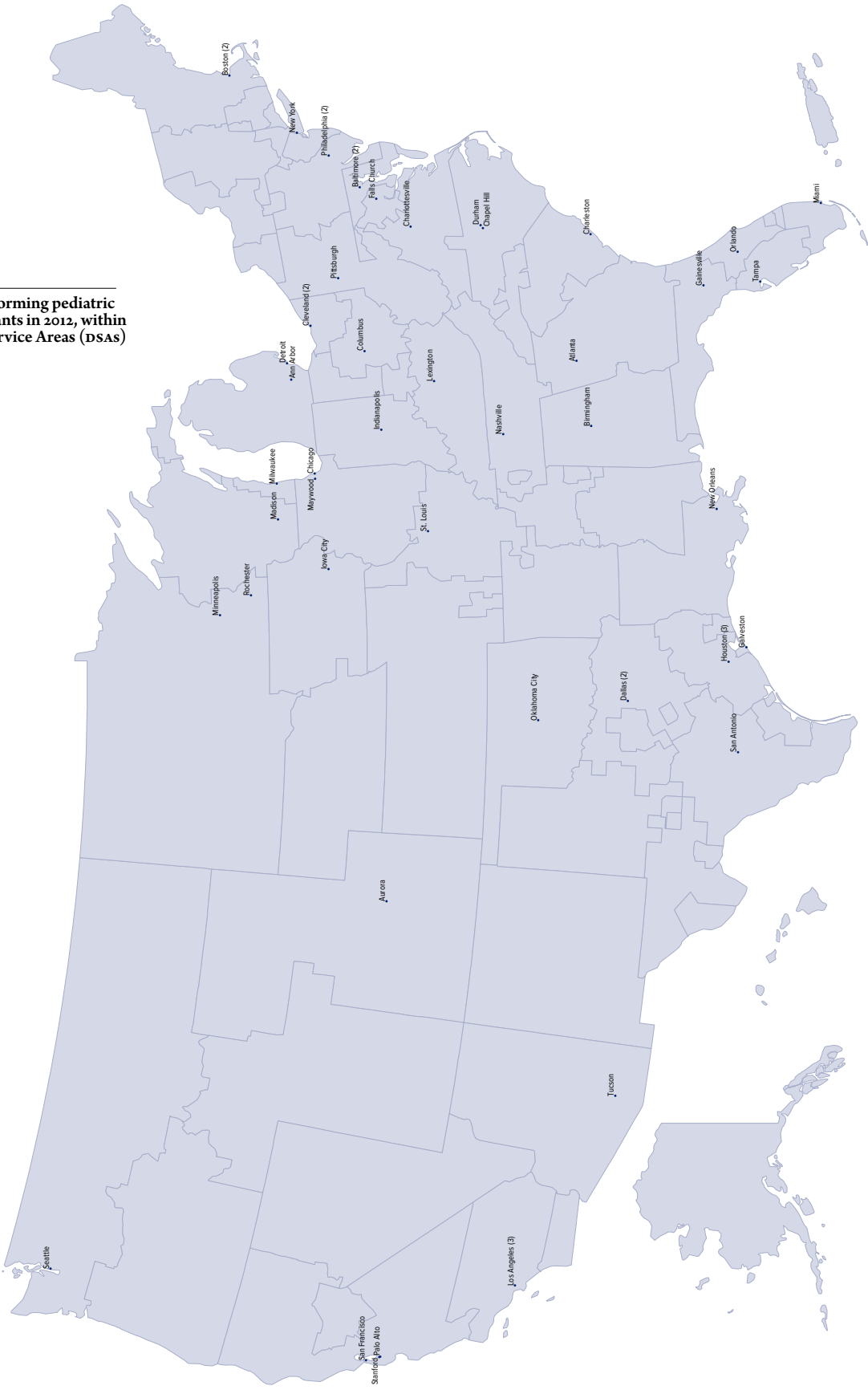
LU 7.7 Total calendar-year and per-person per-year (PPPY) Medicare costs (\$) spent on lung transplant recipients, 2008, 2009, & 2010

Costs paid by Medicare in each calendar year among recipients alive with graft function in the given year, regardless of Medicare eligibility at the time of transplant. Costs incurred after transplant failure are excluded. Values for cells with 9 or fewer patients are suppressed.

LU 8.1 Centers performing adult lung transplants in 2012, within Donation Service Areas (DSAs)



LU 8.2 Centers performing pediatric lung transplants in 2012, within Donation Service Areas (DSAs)



transplant programs 172
 organs recovered per donor 173
 organs transplanted per donor 174
 organ discards | expanded criteria donors 176
 donations after cardiac death | waiting time 177
 organ use 178

OPTN/SRTR 2012 Annual Data Report:

deceased organ donation

ABSTRACT The status of deceased organ donation is assessed using several metrics, including donation/conversion rate (how often at least one organ is recovered for transplant from an eligible death), organ yield (ratio of observed/expected numbers of organs transplanted), and rate of organs discarded (number of organs discarded divided by the number of organs recovered for transplant). The 2012 donation/conversion rate was 72.5 eligible donors per 100 eligible deaths, slightly lower than the 2011 rate but higher than in previous years. The 2011-2012 yield ratio varied by donation service area from 0.91 (fewer organs transplanted per donor than expected) to 1.09 (more than expected), and also varied for specific organs. The mean number of organs transplanted per donor in 2012 was 3.02, lower than in 2011 and 2010; this number varied by donation service area from 2.04 to 3.76. The number of organs discarded is calculated by subtracting the number of organs transplanted from the number recovered for transplant; this number is used to calculate the discard rate. The discard rate in 2012 for all organs combined was 0.14 per recovered organ, slightly higher than in 2011 and 2010; it varied by donation service area and organ type.

KEY WORDS Deceased organ donation, donation/conversion rate, organ discard rate, organ yield.

Luke wore the "tree of life" symbol proudly on his arm and close to his heart. His awesome commitment of organ donation gave the gift of life to four people. His donation also enhanced the lives of over 40 others. Please consider organ donation.

Jo Anne & Tim, Luke's mother and father

Introduction

The status of deceased organ donation is assessed using several metrics, including donation/conversion rate, organ yield, and rate of organs discarded. These metrics have assumed increasing importance in light of decreasing numbers of eligible deaths over the past few years and fewer organs transplanted in 2012 than in the preceding two years. This chapter describes these metrics and compares them across the 58 donation service areas (DSAs).

DEFINITIONS OF TERMS RELATED TO DECEASED ORGAN DONATION

- **Eligible death:** Death of a person aged 70 years or younger who is legally declared brain dead according to hospital policy and does not exhibit any of the exclusions listed in Figure 1.1.
- **Donor:** A person from whom at least one organ was procured for the purpose of transplant, regardless of whether the organ was transplanted.
- **Eligible donor:** A donor whose death met the definition of eligible death.
- **Donation/conversion rate:** Number of eligible donors per 100 eligible deaths.
- **Organ-specific donation/conversion rate:** Number of donors of each organ type who met eligibility criteria per 100 eligible deaths.
- **Organs recovered per donor (ORPD):** Total number of organs recovered divided by the number of donors, not limited to eligible deaths.
- **Organs transplanted per donor (OTPD):** Total number of organs transplanted divided by the number of donors, not limited to eligible deaths.

- **Organ yield:** Ratio of observed to expected numbers of organs transplanted; expected numbers based on national experience with similar donors.
- **Rate of organs discarded:** Number of organs discarded is calculated by subtracting the number of organs transplanted from the number of organs recovered for the purpose of transplant; the discard rate is then calculated by dividing the number of organs discarded by the number of organs recovered for the purpose of transplant.
- **Expanded criteria donors (ECD):** Donors aged 60 years or older, or aged 50-59 years with two of the following: hypertension, terminal creatinine >1.5mg/dL, or death from cerebrovascular accident. This definition was developed for kidney donors. However, we have used this to classify donors in general.

Eligible Deaths

Organ procurement organizations (OPOs) are required to report all eligible deaths to the Organ Procurement and Transplantation Network (OPTN). For reporting purposes, an eligible death is defined as the death of a person aged 70 years or younger who is legally declared brain dead according to hospital policy and does not exhibit any of the exclusions listed in OPTN policy (Figure 1.1). In 2012, 8944 eligible deaths were reported by OPOs, reduced from 9023 reported in 2011 and 9035 in 2010.

Donation/Conversion Rate

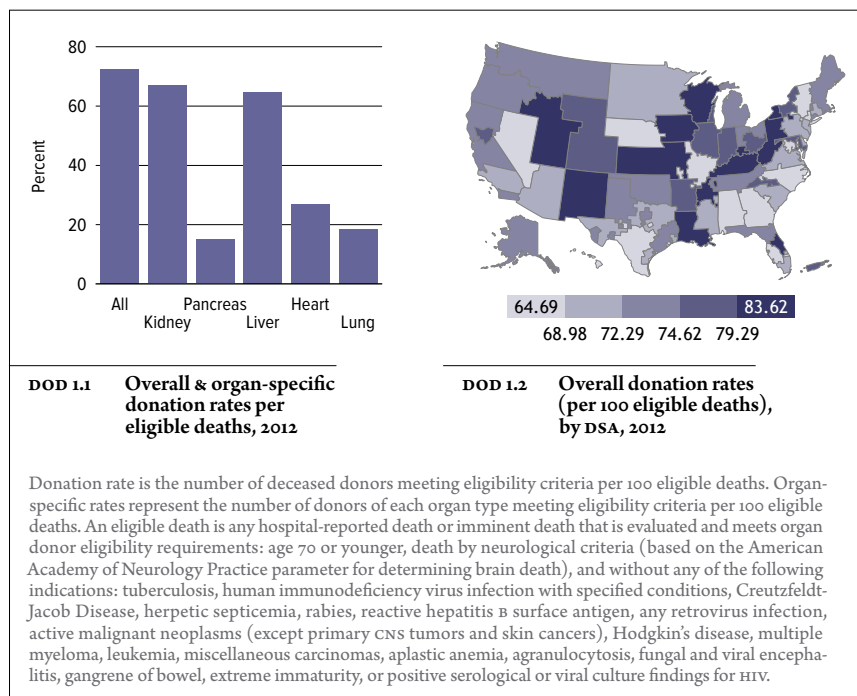
The donation/conversion rate is a measure of how often an eligible death becomes a donor (at least one organ recovered for the purpose of transplant). It is calculated as the number

of eligible donors (donors whose deaths met the definition of eligible death) per 100 eligible deaths. In 2012, the donation/conversion rate was 72.5 eligible donors per 100 eligible deaths, a slight decline from 72.9 in 2011 (Figure 1.1), but higher than rates in 2009 (69.4) and 2010 (71.7). Organ-specific donation/conversion rates are calculated as the numbers of eligible donors of each specific organ type per 100 eligible deaths. In 2012, the donation/conversion rate for kidneys was 67.0 (1 or 2 kidneys recovered), higher than the rate of 64.7 for livers; both of these rates were higher than the rates for thoracic organs and pancreata.

The heart donation/conversion rate was 27.0, higher than the rate of 18.5 for lung conversion (1 or 2 lungs recovered). Unadjusted donation/conversion rates varied by DSA (Figure 1.2).

Organs Recovered per Donor

The number of organs recovered per donor (ORPD) is calculated by dividing the total number of organs recovered by the number of donors. The number of ORPD was 3.50 in 2012, slightly lower than 3.54 in 2011 and 3.58 in 2010. Since 2000, this value has ranged from 3.48 to 3.60 (Figure 2.1). In 2012, ORPD varied substantially by DSA, ranging from 2.75 to 4.13 (Figures 2.2, 2.3). Numbers of kidneys recovered per donor ranged from 1.54 to 1.97; pancreata, from 0.06 to 0.40 (unlike in 2011, islets are no longer counted as organs); and livers,



from 0.61 to 0.96. Numbers of intestines recovered per donor ranged from 0.0 to 0.08; hearts, from 0.0 to 0.44; and lungs, from 0.07 to 0.78 (Figure 2.2). The number of ORPD represents a mix of donor types such as standard criteria donors (SCD), expanded criteria donors (ECD), or donation after circulatory death (DCD) donors.

Organs Transplanted per Donor and Organ Yield

The mean number of organs transplanted per donor (OTPD) was 3.02 in 2012, slightly lower than 3.07 in 2011 and 3.10 in 2010 (Figure 3.1). Since 2000, this value has ranged from 3.00 to 3.24. In an unadjusted analysis, not accounting for SCD, ECD, and DCD donor types, the number of OTPD varied substantially by DSA, ranging from 2.04 to 3.76 (Figures 3.2, 3.3).

The ratio of observed to expected organs transplanted, or yield, is the metric used by OPTN to identify OPOs that require review for quality improvement purposes. The aggregate and organ-specific yield metrics for each OPO are publically available on the Scientific Registry of Transplant Recipients website (<http://www.srtr.org/opo/Default.aspx>). This adjusted analysis based on a 2-year cohort also suggests opportunities to share best practices from DSAs with higher than expected organ-specific yields to improve the overall yield across the country. The yield metric shown compares the number of organs transplanted (observed) in 2011-2012 with the number of organs that would be expected to be transplanted in 2011-2012 based on the national experience with similar donors (expected). A ratio, expressed as observed/expected organs transplanted, of less than 1 indicates that fewer organs were transplanted than would be expected based on the national models for that organ. A ratio of greater than 1 indicates that more organs were transplanted than would be expected. In

2011-2012, the donor yield observed/expected ratio for total organs varied by DSA from 0.91 to 1.09 (Figure 3.4). The mean observed/expected ratio for kidneys varied from 0.89 to 1.14; for pancreata, from 0.24 to 2.71; for livers, from 0.77 to 1.16; for intestines, from 0 to 5.06; for hearts, from 0 to 1.22; and for lungs, from 0.38 to 1.43 (Figure 3.5).

As expected, the number of OTPD from SCDs was higher than the number from ECDs or DCD donors (Figure 3.6). Donors who are not ECD or DCD are considered SCD. In 2012, 3.65 organs were transplanted per donor from SCDs compared with 1.87 from ECDs and 1.91 from DCD donors. More kidneys were transplanted per donor from SCDs than from DCD donors or ECDs: 1.66, 1.60, and 0.89, respectively (Figure 3.7). As in past years, the numbers of kidneys transplanted per donor from DCD donors and from SCDs are similar. In contrast, for non-renal organs, the number of OTPD from SCDs was higher than the numbers for ECDs and DCD donors (Figure 3.8). The number of livers from ECD donors rose from 847 in 2000 to 1313 in 2012, and lungs from ECD donors rose from 74 in 2000 to 362 in 2012. Numbers of livers and lungs from DCD donors are smaller but increasing: 33 liver donors in 2000 and 253 in 2012; 0 lung donors in 2000 and 32 in 2012.

Discard Rate

The number of organs discarded is calculated by subtracting the number of organs transplanted from the number of organs recovered for the purpose of transplant. The discard rate is then calculated by dividing the number of organs discarded by the number of organs recovered for the purpose of transplant. The discard rate in 2012 for all organs combined was 0.14 per recovered organ, slightly higher than the rate of 0.13 in 2010 and 2011 (Figure 4.1). The pancreas discard rate remained

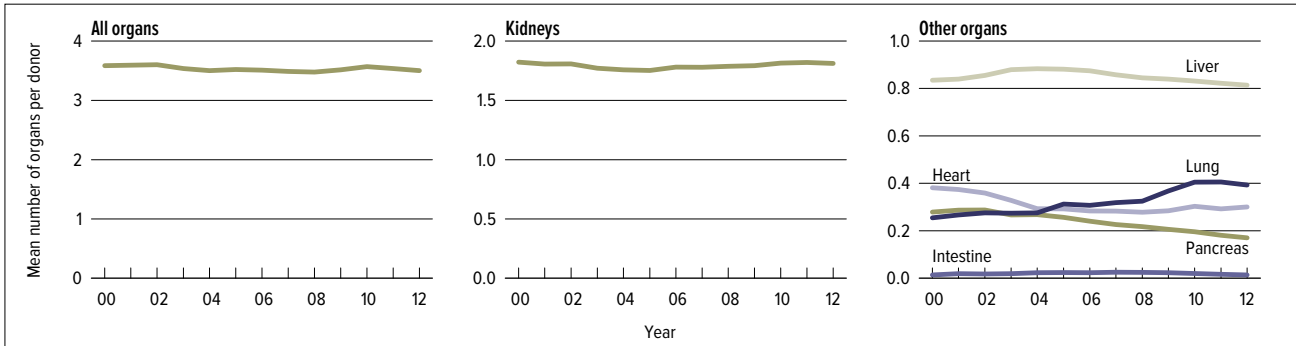
highest, but it declined to 0.25 in 2012 from 0.27 in 2011. The kidney discard rate increased slightly to 0.19 in 2012 from 0.18 in 2011. The liver discard rate was unchanged, at 0.10 for livers in 2012 and 2011 (Figure 4.1). Discard rates varied substantially by DSA (Figure 4.2) and by organ type.

In 2012, use of kidneys, livers, and lungs from ECDs and DCD donors varied by DSA (Figures 5.1 and 6.1). To quantify ECD use, the number of ECD organs transplanted is divided by the number of all organs (SCD+ECD+DCD) transplanted. This calculation was performed for each organ type (kidney, pancreas, liver, and lung). The largest variation occurred for livers; livers from ECD donors represented 2% to 46% of all livers transplanted by DSA (Figure 5.1). Variations for lungs and kidneys were next largest; lungs from ECD donors represented 0% to 38% of all lungs transplanted by DSA, and ECD kidneys 3% to 25% of all kidneys transplanted (Figure 5.1). Similarly, use of kidneys and livers from DCD donors varied by DSA. DCD kidneys represented 1% to 35% of all kidneys transplanted by DSA, and DCD livers represented 0% to 15% of all livers transplanted (Figure 6.1). Waiting times for deceased donor transplants also varied by DSA in 2012 (Figure 7.1). Average waiting times across the 58 DSAs were longest for kidney transplants, on average 26 months compared with 12 for pancreas, 10 for intestines, 4 for livers, 3 for hearts, and 3 for lungs. These average waiting times apply only to candidates who underwent transplant, and do not account for candidates who did not undergo transplant.

In 2012, at least one organ was procured for the purpose of transplant from 8144 donors, slightly more than the 8128 donors in 2011 (Figure 8.1). Of the 16,288 kidneys from these donors, 5720 left, 5617 right, and 328 *en bloc* kidneys were transplanted. This represents 74% of all kidneys, considering

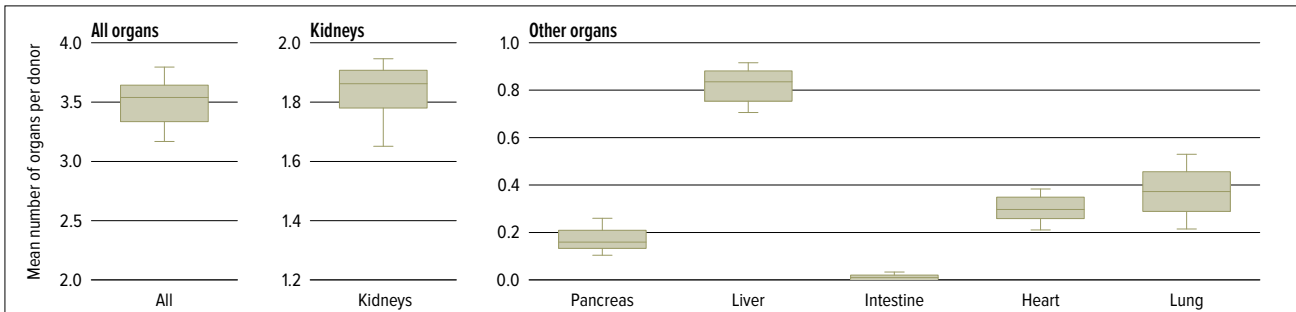
en bloc transplants as two kidneys. Reasons for not using donor kidneys are listed in Figure 8.1. The most common reason for not procuring a kidney was poor organ function. Of kidneys recovered, 1252 left, 1327 right, and 90 *en bloc* were not transplanted. The most common reason for not transplanting a procured left or right kidney was biopsy findings (Figure 8.1). From the 8144 donors, only 1046 pancreas allografts (12.84%) were transplanted; another 520 were recovered for the purpose of transplant but not transplanted (Figure 8.2). From the 8144 donors, only 5942 liver allografts (72.96%) were transplanted; another 691 were recovered but not transplanted (Figure 8.3). The most common reason for not transplanting recovered livers was biopsy findings. Reasons for not transplanting recovered livers differ from reasons for not procuring a liver. The most common reason for not procuring a liver was, “ruled out after evaluation in the operating room” (Figure 8.3). For remaining organs, the numbers procured for transplant and not used were smaller (Figure 8.4-8.6).

organs recovered per donor



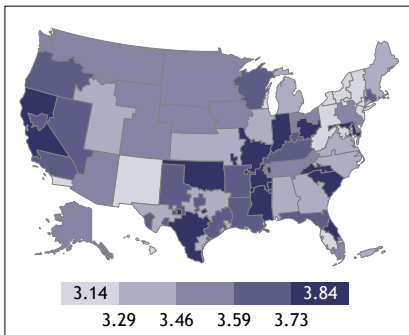
DOD 2.1 Organs recovered per donor (ORPD)

Organs recovered per donor is the average number of organs recovered per donor, calculated as the sum of recovered organs and by organ type, i.e., in the case of kidneys recovered, up to two kidneys can be recovered from an individual donor, while only one heart can be recovered from each donor. Pancreata recovered for islet transplantation are excluded.



DOD 2.2 Organs recovered per donor (ORPD), by DSA, 2012

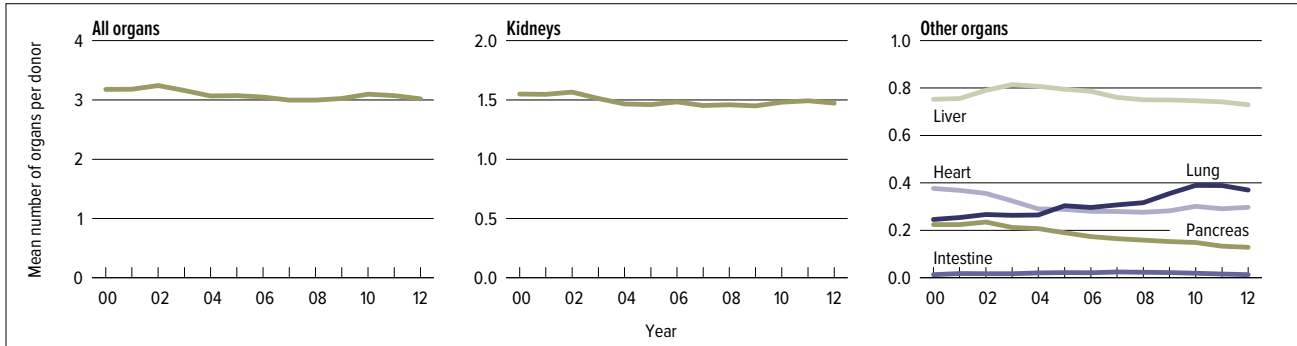
Organs recovered per donor is the average number of organs recovered per donor, calculated as the sum of recovered organs and by organ type, i.e., in the case of kidneys recovered, up to two kidneys can be recovered from an individual donor, while only one heart can be recovered from each donor. Means of DSA-level means are shown. Pancreata recovered for islet transplantation are excluded.



DOD 2.3 Organs recovered per donor (ORPD), by DSA, 2012

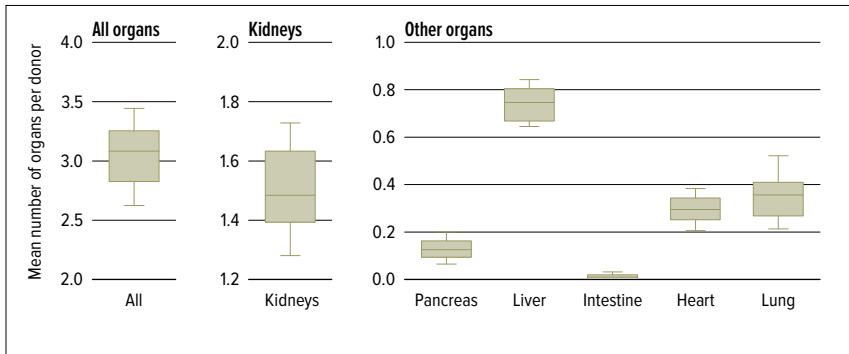
Organs recovered per donor is the average number of organs recovered per donor, calculated as the sum of recovered organs, i.e., in the case of kidneys recovered, up to two kidneys can be recovered from an individual donor, while only one heart can be recovered from each donor. Pancreata recovered for islet transplantation are excluded.

organs transplanted per donor



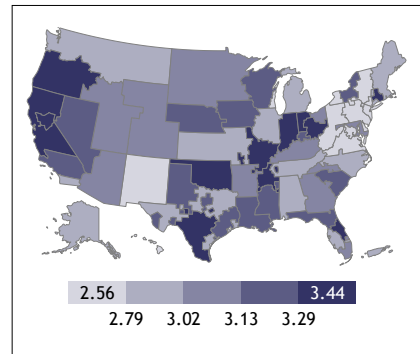
DOD 3.1 Organs transplanted per donor (OTPD)

Organs transplanted per donor is the average number of organs transplanted per donor. Organs divided into segments (liver, lung, pancreas, intestine) may account for more than one transplant, so the number transplanted may exceed the number recovered. Based on a count of recovered organs that are transplanted, which differs from the number of transplant operations. Pancreata recovered for islet transplantation are excluded.



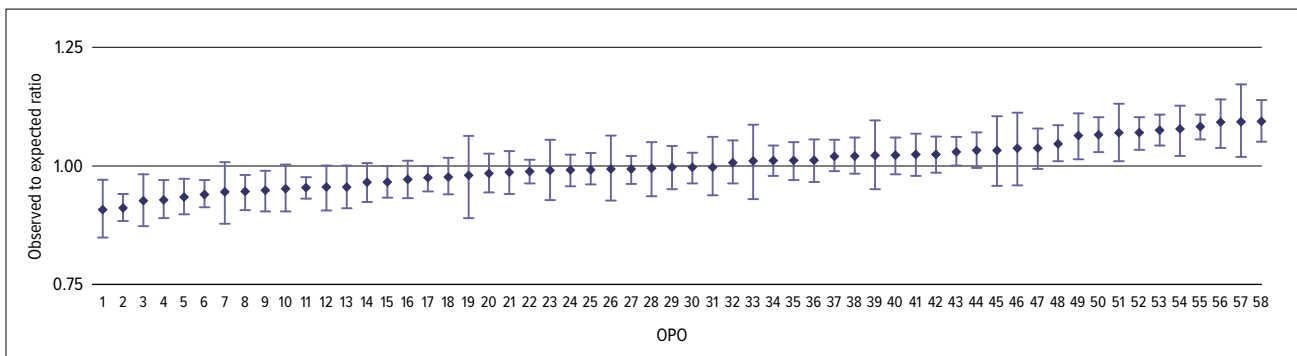
DOD 3.2 Organs transplanted per donor (OTPD), by DSA, 2012

Organs transplanted per donor is the average number of organs transplanted per donor. Organs divided into segments (liver, lung, pancreas, intestine) may account for more than one transplant, so the number transplanted may exceed the number recovered. Based on a count of recovered organs that are transplanted, which differs from the number of transplant operations. Means of DSA-level means are shown. Pancreata recovered for islet transplantation are excluded.



DOD 3.3 Organs transplanted per donor (OTPD), by DSA, 2012

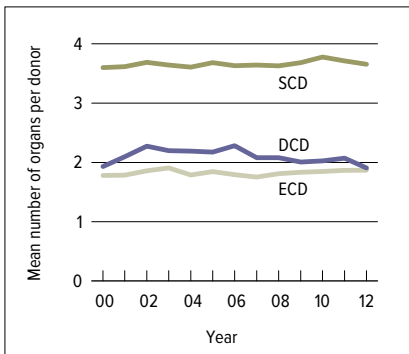
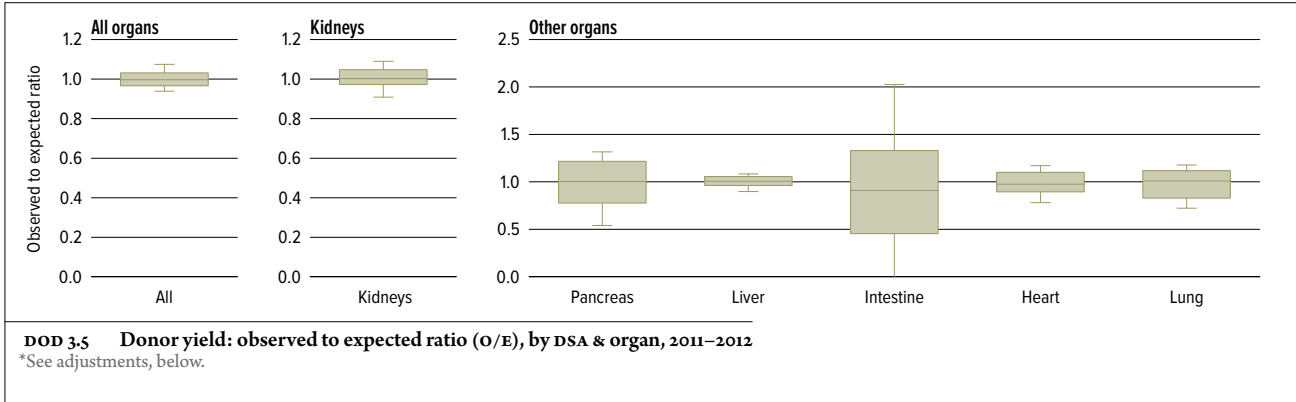
Organs transplanted per donor is the average number of organs transplanted per donor. Organs divided into segments (liver, lung, pancreas, intestine) may account for more than one transplant, so the number transplanted may exceed the number recovered. Based on a count of recovered organs that are transplanted, which differs from the number of transplant operations. Pancreata recovered for islet transplantation are excluded.



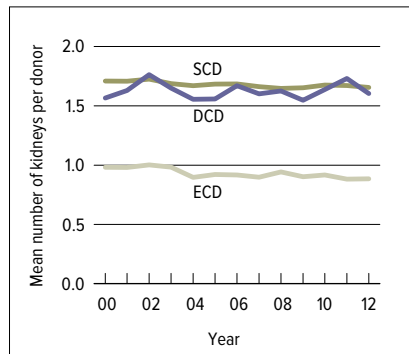
DOD 3.4 Donor yield: observed to expected ratio (O/E), 2011–2012: all organs

Donor yield provides a measure of organs transplanted per donor. Expected yield is estimated from statistical models. These models take into account various characteristics that are not under the control of the OPOs.

organs transplanted per donor

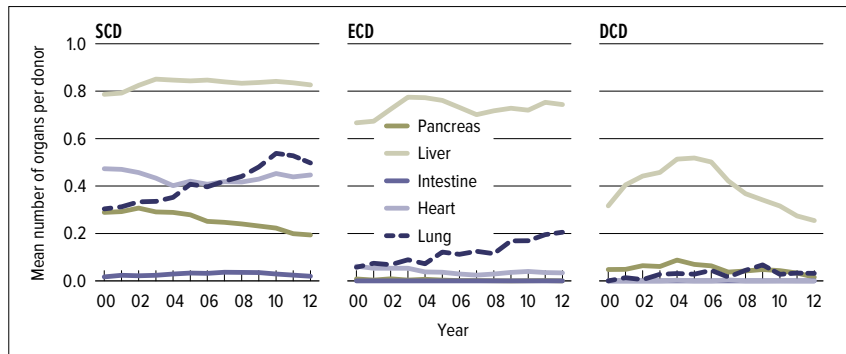


Organs transplanted per donor is the average number of organs transplanted per donor. Organs divided into segments (liver, lung, pancreas, intestine) may account for more than one transplant, so the number transplanted may exceed the number recovered. Based on a count of recovered organs that are transplanted, which differs from the number of transplant operations. Pancreata recovered for islet transplantation are excluded.



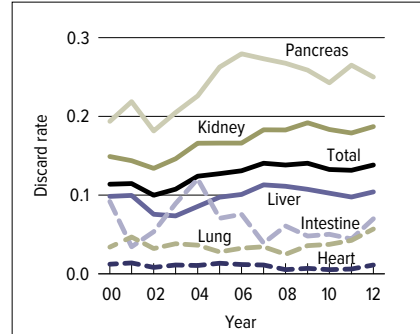
Organs transplanted per donor is the average number of organs transplanted per donor. Organs divided into segments (liver, lung, pancreas, intestine) may account for more than one transplant, so the number transplanted may exceed the number recovered. Based on a count of recovered organs that are transplanted, which differs from the number of transplant operations. Pancreata recovered for islet transplantation are excluded.

*Models adjust for the following:
 Kidney: age, gender, blood type, cause of death, circumstances of death, mechanism of death, clinical infection present, cigarette use, cocaine use, heavy alcohol consumption, cdc high risk donor, history of diabetes, insulin dependence, history of hypertension, history of cancer, DCD, cardiac arrest after brain death, hepatitis B surface antigen, hepatitis B core antibody, hepatitis C antibody, serum creatinine, organ recovered outside the contiguous 48 states?
 Pancreas: age, BMI, race/ethnicity, blood type, cause of death, circumstances of death, mechanism of death, cocaine use, heavy alcohol consumption, CDC high risk donor, history of diabetes, insulin dependence, history of hypertension, history of cancer, dcd, lung pO₂ terminal value/FiO₂, hepatitis B surface antigen, hepatitis B core antibody, hepatitis C antibody, serum creatinine, organ recovered outside the contiguous 48 states?
 Liver: age, BMI, race/ethnicity, blood type, cause of death, circumstances of death, clinical infection present, cigarette use, cocaine use, heavy alcohol consumption, CDC high risk donor, history of diabetes, insulin dependence, DCD, DCD controlled, cardiac arrest after brain death, lung pO₂ terminal value/FiO₂, hepatitis B surface antigen, hepatitis B core antibody, hepatitis C antibody, serum creatinine, organ recovered outside the contiguous 48 states?
 Intestine: history of diabetes, insulin dependence, dcd, hepatitis b surface antigen.
 Heart: age, BMI, gender, race/ethnicity, blood type, cause of death, mechanism of death, clinical infection present, cigarette use, cocaine use, other drug use, CDC high risk donor, history of diabetes, history of hypertension, DCD, cardiac arrest after brain death, lung pO₂ terminal value/FiO₂, hepatitis B surface antigen, hepatitis B core antibody, hepatitis C antibody, serum creatinine, organ recovered outside the contiguous 48 states?
 Lung: age, BMI, gender, race/ethnicity, blood type, cause of death, circumstances of death, mechanism of death, clinical infection present, cigarette use, cocaine use, other drug use, CDC high risk donor, insulin dependence, history of cancer, DCD, cardiac arrest after brain death, lung pO₂ terminal value/FiO₂, hepatitis B surface antigen, hepatitis B core antibody, hepatitis C antibody, serum creatinine, organ recovered outside the contiguous 48 states?



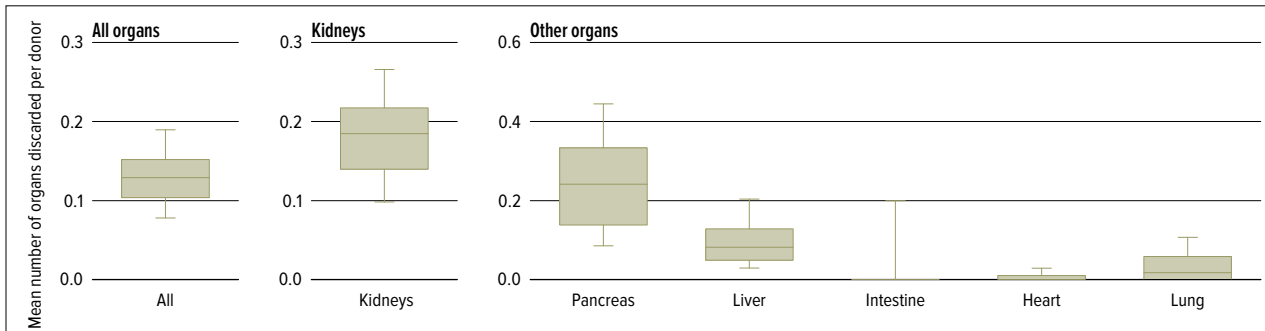
Organs transplanted per donor is the average number of organs transplanted per donor. Organs divided into segments (liver, lung, pancreas, intestine) may account for more than one transplant, so the number transplanted may exceed the number recovered. Based on a count of recovered organs that are transplanted, which differs from the number of transplant operations. Pancreata recovered for islet transplantation are excluded.

organ discards | expanded criteria donors



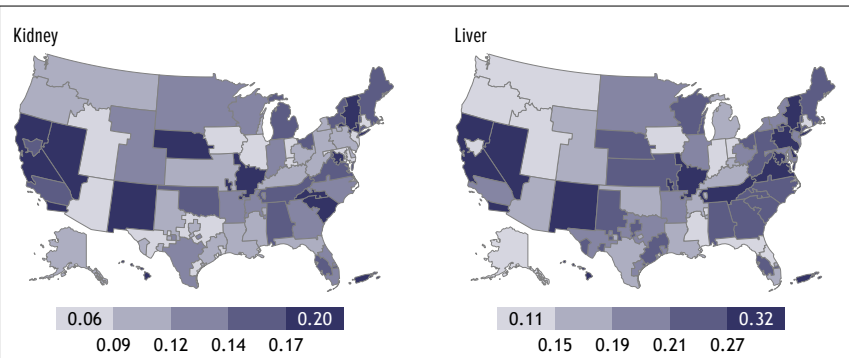
DOD 4.1 Organ discard rates for organs recovered for transplantation

Organ discard rate is calculated as the difference between the number of organs recovered and the number of organs transplanted, divided by the number of organs recovered. Pancreata recovered for islet transplantation are excluded.



DOD 4.2 Variation in organ discard rates, by DSA, 2012

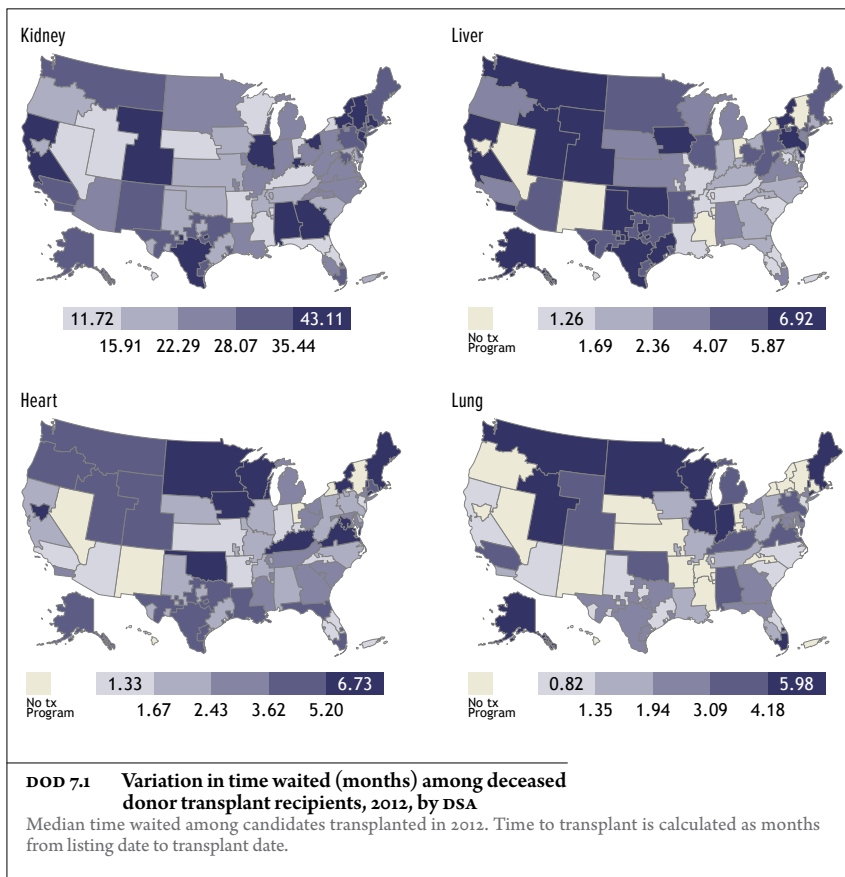
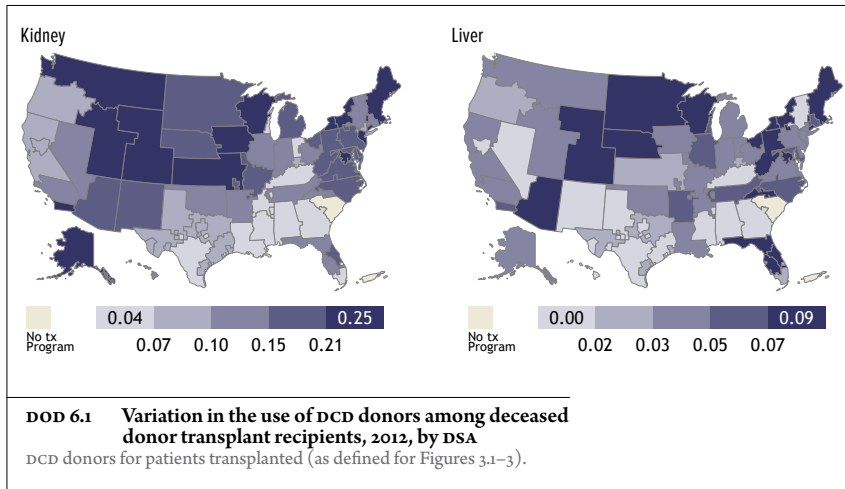
Organ discard rate is calculated as the difference between the number of organs recovered and the number of organs transplanted, divided by the number of organs recovered. Pancreata recovered for islet transplantation are excluded.



DOD 5.1 Variation in the use of ECD donors among deceased donor transplant recipients, 2012, by DSA

ECD donors for patients transplanted (as defined for Figures 3.1–3).

donations after cardiac death | waiting time



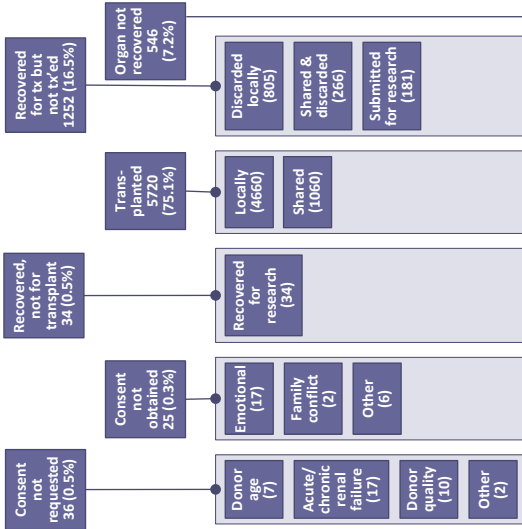
DOD 8.1 organ use: kidney

Kidney

2012: 8144 donors (16288 kidneys)

Reported by left/right: 7613 donors (93.5%)

Left

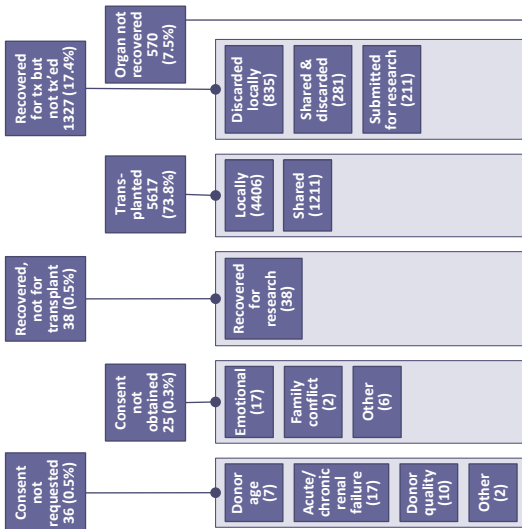


Unreported (2)
Too old on pump (4)
Too old on ice (17)
Vascular damage (16)
Ureteral damage (3)
Donor medical history (7)
Donor social history (4)
Positive hepatitis (9)
Warm ischemic time too long (14)
Organ not as described (3)

Biopsy findings (445)
Recipient determined to be unsuitable for tx in OR (8)
Poor organ function (102)
Infection (3)
Diseased organ (41)
Donor social history (7)
Anatomical abnormalities (106)
No recipient located; list exhausted (263)
Other (185)

Poor organ function (261)
Positive hepatitis (4)
Diseased organ (35)
Anatomical abnormalities (not valid for PA or PA segments) (8)
No recipient located (24)
Donor medical history (71)
Donor social history (7)
Biopsy findings (1)
Organ refused by all regional programs (14)
Organ refused by all national programs (41)

Right

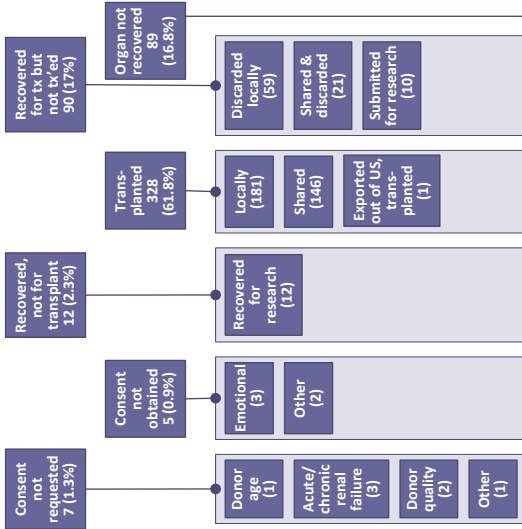


Unreported (1)
Too old on pump (4)
Too old on ice (25)
Vascular damage (20)
Ureteral damage (1)
Donor medical history (8)
Donor social history (6)
Positive hepatitis (6)
Warm ischemic time too long (15)
Organ not as described (1)

Biopsy findings (442)
Recipient determined to be unsuitable for tx in OR (4)
Poor organ function (112)
Infection (2)
Diseased organ (48)
Anatomical abnormalities (102)
No recipient located; list exhausted (307)
Other (201)

Poor organ function (258)
Positive hepatitis (4)
Diseased organ (39)
Anatomical abnormalities (not valid for PA or PA segments) (14)
No recipient located (23)
Donor medical history (75)
Donor social history (7)
Organ refused by all regional programs (14)
Organ refused by all national programs (44)

Reported en bloc: 531 donors (6.5%)



Too old on ice (4)
Vascular damage (3)
Donor social history (1)
Organ trauma (1)
Biopsy findings (19)
Recipient determined to be unsuitable for tx in OR (1)
Poor organ function (11)
Diseased organ (5)
Anatomical abnormalities (9)

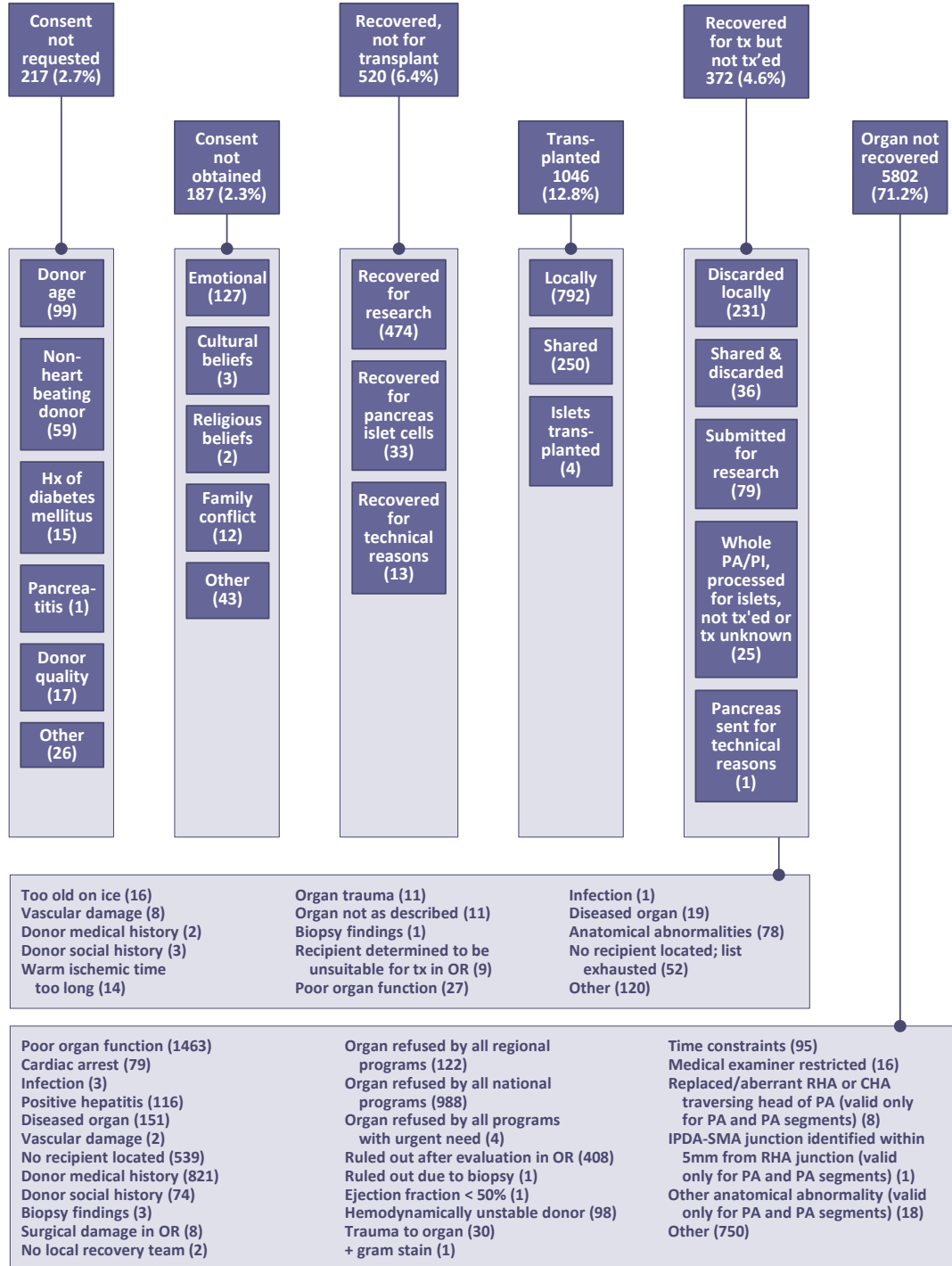
No recipient located; list exhausted (18)
Other (18)

Poor organ function (29)
Positive hepatitis (1)
Diseased organ (12)
Vascular damage (1)
No recipient located (7)
Donor medical history (10)
Donor social history (1)
Organ refused by all national programs (12)
Ruled out after evaluation in OR (10)
Other (6)

DOD 8.2 organ use: pancreas

Pancreas

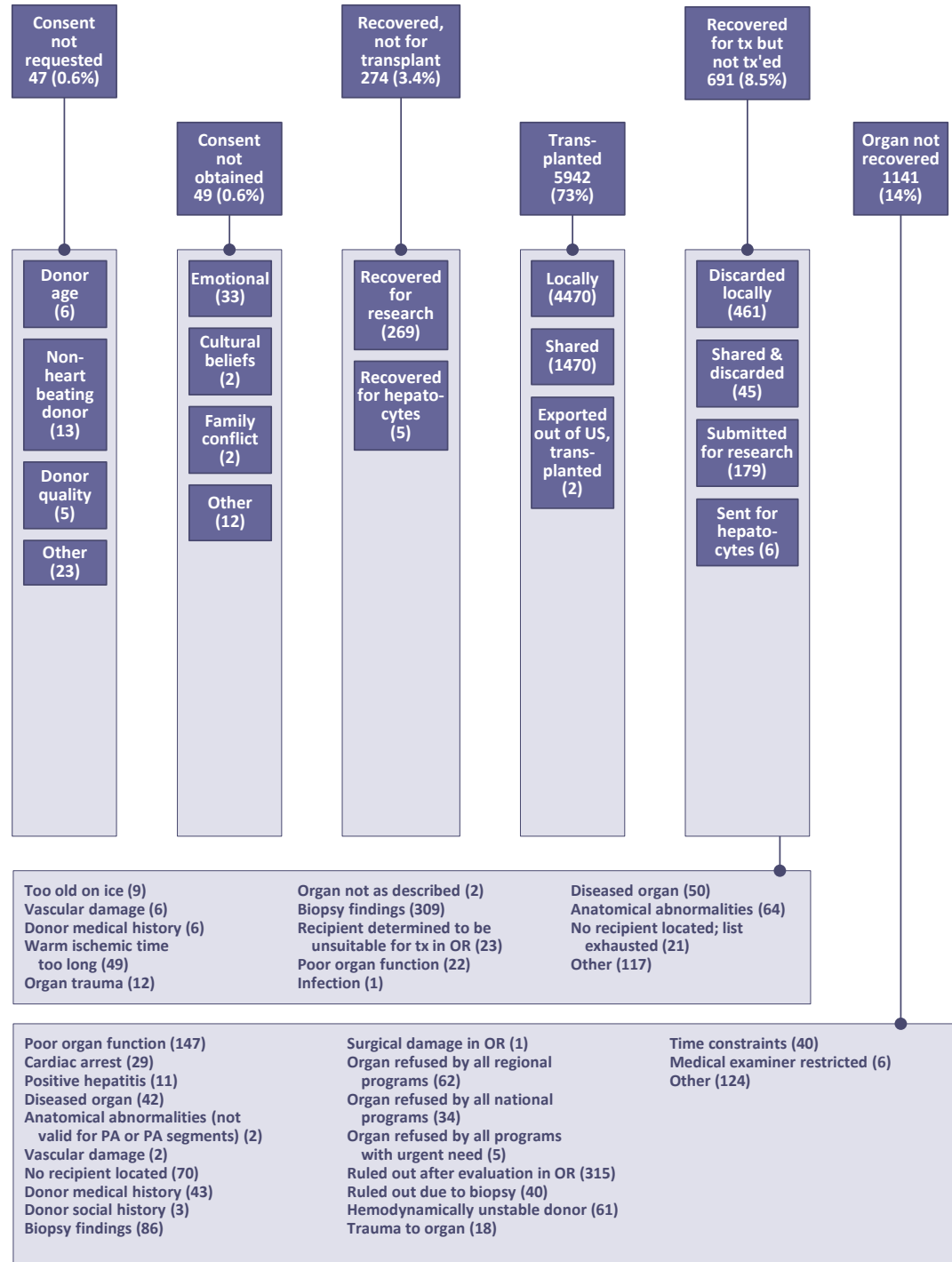
2012: 8144 donors



DOD 8.3 organ use: liver

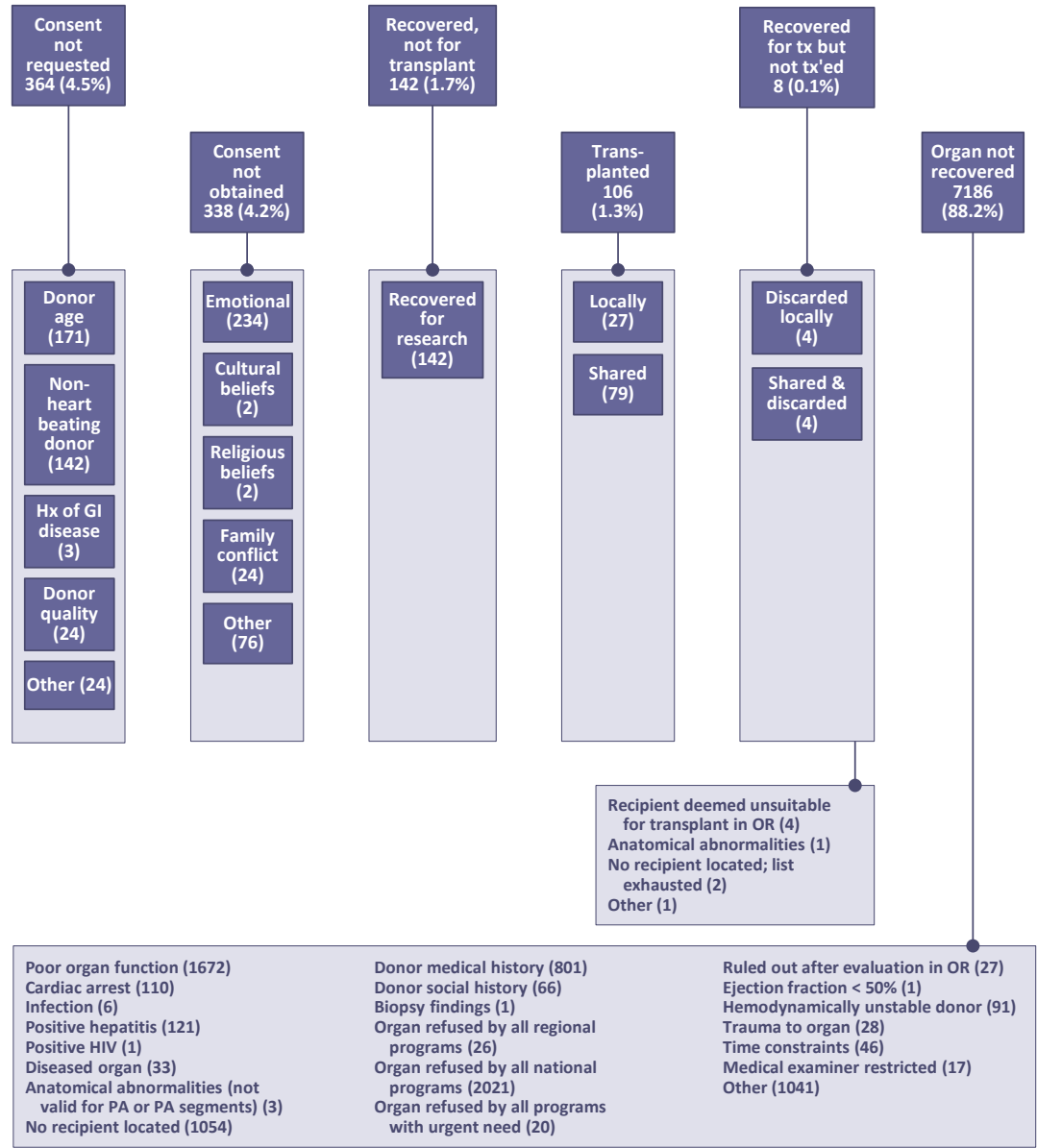
Liver

2012: 8144 donors



DOD 8.4 organ use: intestine

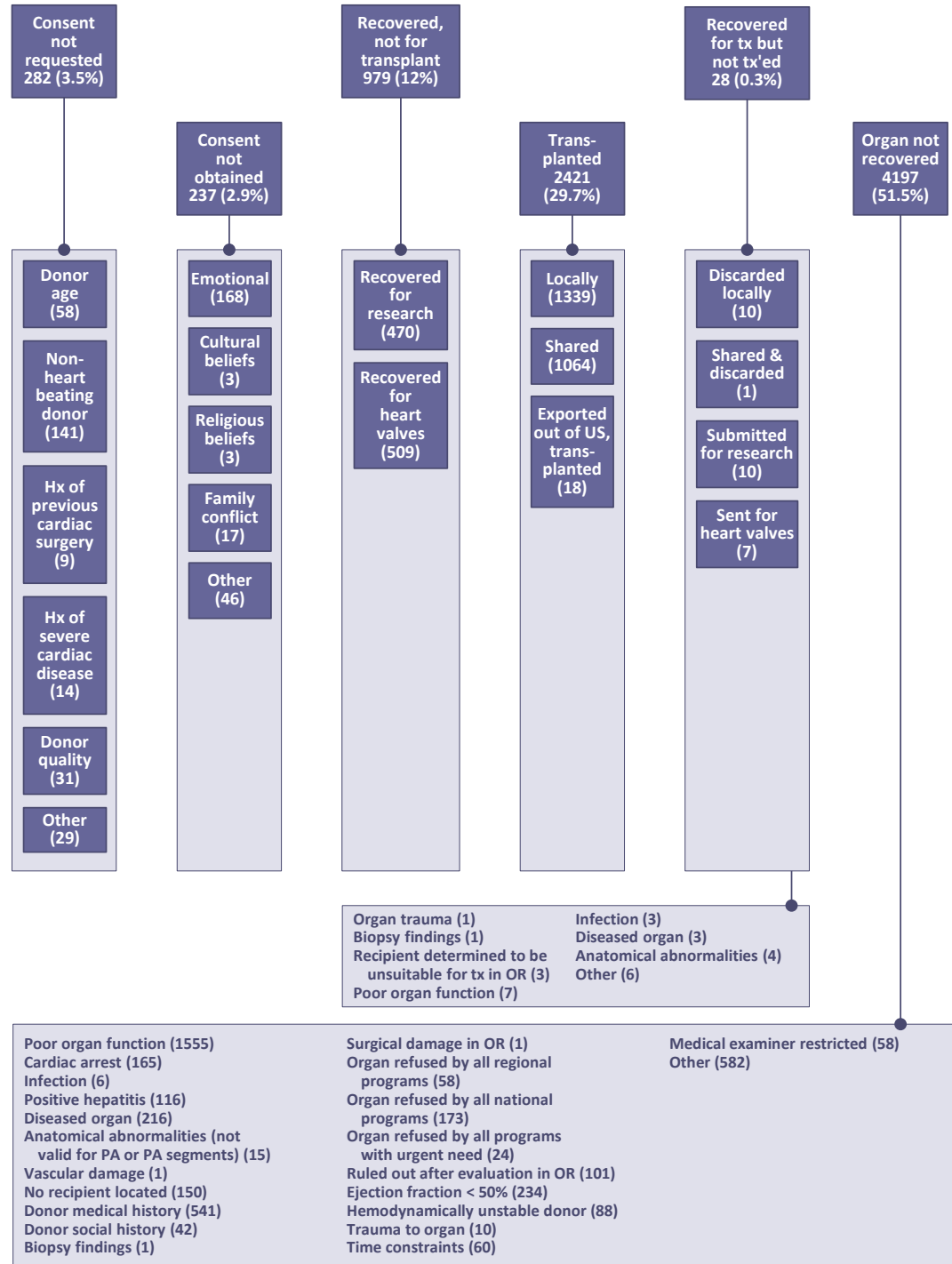
Intestine 2012: 8144 donors



DOD 8.5 organ use: heart

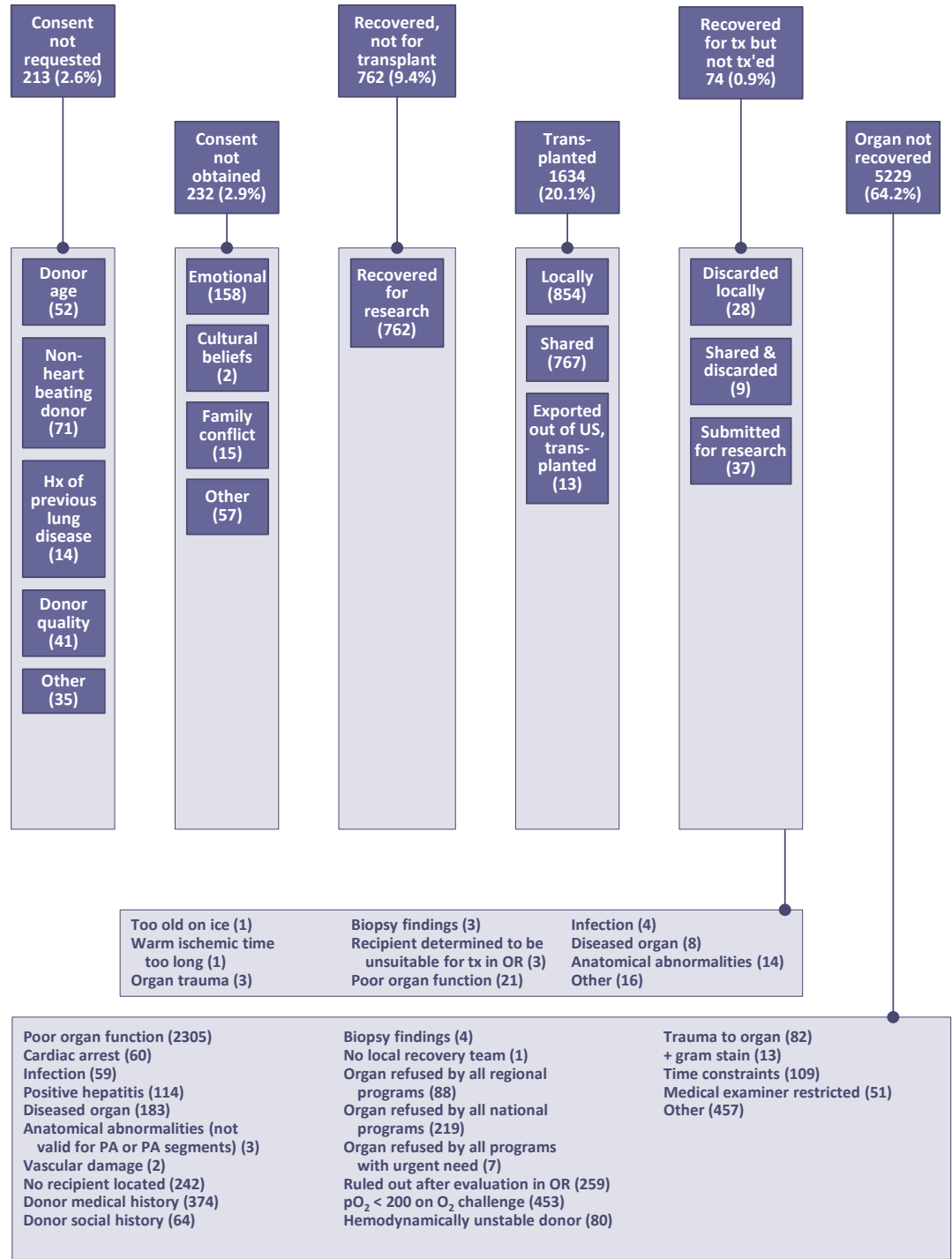
Heart

2012: 8144 donors



DOD 8.6 organ use: lung

Lung 2012: 8144 donors





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glossary 188

If I had a couple of minutes with my son now, I could smile and say, "You have saved and enhanced the lives of over 50 people." I'm very proud of that.

donor mother

methods

PRA AND CPRA

For kidney and pancreas transplant recipients prior to December 1, 2007, PRA at the time of transplant is the value of the most recently recorded PRA. If that value is missing, we use the peak PRA value known at the time of transplant. In 2004, the OPTN Recipient Histocompatibility form changed the PRA collection method from overall PRA to Class I and Class II PRA. From 2004 through 2007, we use the maximum of the Class I and Class II values. From December 2007 through October 2009, we incorporate calculated PRA (CPRA) if the value is greater than zero. In this time frame, we use the maximum of measured PRA and CPRA. From October 2009 to present, we use the maximum of CPRA, measured PRA, and allocation PRA. A similar approach is used for PRA and CPRA among kidney and pancreas candidates.

For liver, intestine, heart, and lung transplant recipients, PRA at the time of transplant is the value of the most recently recorded PRA. If that value is missing, we use the peak PRA value known at the time of transplant. In 2004, the OPTN Recipient Histocompatibility form changed the PRA collection method from overall PRA to Class I and Class II PRA. In these years, we use the maximum of the Class I and Class II values.

INCIDENCE

Incidence of posttransplant outcomes (diabetes, PTLT, etc.) is computed using competing risk methods. Outcomes observations are not censored at death. In prior years, most outcomes were censored at death, providing an artificially increased incidence of the outcome under consideration.

GRAFT FAILURE

Unless otherwise specified, “graft failure” refers to graft failure due to any cause, including death and retransplant. For kidney failure, this also includes return to maintenance dialysis. “Graft survival” similarly refers to the absence of all-cause graft failure. Graft failure is computed using competing risk methods.

HALF-LIFE

Graft half-life and conditional half-life estimates were computed using a “period” method, which is different from the method previously used. In the past, conditional half-life estimates relied on the rarely true assumption of constant hazard after the first posttransplant year, and extrapolated the survival curve to its half-life based on that early hazard. The “period” method constructs a survival curve until the half-life differently. If the half-life of a cohort in a given year is observed, then the survival curve is constructed using the Kaplan-Meier method based on the observed data of this cohort. Otherwise, we construct the survival curve using the data from the cohort for the observed part and “borrow” data from earlier cohorts for the rest. For example, the 2007 half-life estimate for kidney graft survival is based on observed and borrowed data. For patients who underwent transplant in 2007, we have observed 5-year survival data through 2012. We extrapolate this survival curve to its half-life by using the observed sixth-year failure rate of the 2006 cohort as the sixth-year failure rate of the 2007 cohort, the seventh-year failure rate of 2005 cohort as the seventh-year failure rate of the 2007 cohort, and so on. Conditional half-life estimates are similarly computed, but limited to patients with one year of graft survival.

ALIVE WITH FUNCTION

For a given year and organ type, counts of recipients alive with function include all recipients of that organ who underwent transplant prior to June 30 of the given year and who have no evidence of graft loss or death. Multi-organ recipients are counted once per organ. A heart-lung recipient, for example, is included in the counts of heart recipients and of lung recipients alive with function. A kidney-alone recipient who underwent transplant in January 2000, and who lost graft function in November 2010 is counted as alive with function every year from 2000 through 2010. Recipients who are lost to follow-up are assumed to be alive with a functioning graft until evidence, usually a death date, contradicts this assumption.

RATES BY SUBGROUP

When rates are shown by subgroup (i.e., sex, race, primary cause of disease), the numerator and denominator are computed exclusively within those groups. For example, for pretransplant mortality by race group, the numerator for each race group is the number of deaths in that race group during the interval described. The denominator is the total waiting time within each race group in that same time interval. When a characteristic is subject to change over time (i.e., age, PRA), the subgroup variable is updated to use the first known value in a given interval, unless otherwise noted. For example, a wait-listed candidate who was aged 34 years on January 1, 2001, would be included in the 18-34 year age group in 2001, but if that candidate was still listed in 2003, he or she would be included in the 35-49 year age group.

DONOR RISK INDEX

The kidney donor risk index (KDRI) and pancreas donor risk index (PDRI) are measures of donor quality based on donor factors.

$$\text{KDRI}^1: \text{Exp}(-0.0194 \times [\text{if age} < 18 \text{ yrs}] \times [\text{age}-18 \text{ yrs}] + 0.0128 \times [\text{age}-40 \text{ yrs}] + 0.0107 \times [\text{if age} > 50 \text{ yrs}] \times [\text{age}-50 \text{ yrs}] + 0.179 \times [\text{if African-American race}] + 0.126 \times [\text{if hypertensive}] + 0.130 \times [\text{if diabetic}] + 0.220 \times [\text{serum creatinine}-1 \text{ mg/dL}] - 0.209 \times [\text{if serum creatinine} > 1.5 \text{ mg/dL}] \times [\text{serum creatinine} - 1.5 \text{ mg/dL}] + 0.088 \times [\text{if cause of death} = \text{cerebrovascular accident}] - 0.0464 \times \left[\frac{\{\text{height} - 170 \text{ cm}\}}{10} \right] - 0.0199 \times [\text{if weight} < 80 \text{ kg}] \times \left[\frac{\{\text{weight}-80 \text{ kg}\}}{5} \right] + 0.133 \times [\text{if DCD}] + 0.240 \times [\text{if HCV+}])$$

$$\text{PDRI}^2: \text{Exp}(-0.1379 \times [\text{if female}] - 0.03446 \times [\text{if age} < 20 \text{ yrs}] \times [\text{age} - 20 \text{ yrs}] + 0.02615 \times [\text{age} - 28 \text{ yrs}] + 0.19490 \times [\text{if creatinine} > 2.5 \text{ mg/dL}] + 0.2395 \times [\text{if African-American race}] + 0.1571 \times [\text{if Asian race}] - 0.0009863 \times [\text{BMI} - 24] + 0.0333 \times [\text{if BMI} > 25] \times [\text{BMI}-25] - 0.006074 \times [\text{height} - 173 \text{ cm}] + 0.2102 \times [\text{if cause of death} = \text{cerebrovascular accident}] + 0.3317 \times [\text{if DCD}])$$

Expanded version of these indices also include transplant factors, but the donor-specific indices we show in the ADR are limited to donor-specific factors.

¹Rao PS, Schaubel DE, Guidinger MK, Andreoni KA, Wolfe RA, Merion RM, Port FK, Sung RS. A comprehensive risk quantification score for deceased donor kidneys: the kidney donor risk index. *Transplantation*. 2009 Jul 27;88(2):231-6.

²Axelrod DA, Sung RS, Meyer KH, Wolfe RA, Kaufman DB. Systematic evaluation of pancreas allograft quality, outcomes and geographic variation in utilization. *Am J Transplant*. 2010 Apr;10(4):837-45. doi: 10.1111/j.1600-6143.2009.02996.x. Epub 2010 Feb 1.

glossary

Acute rejection The host recognizes the graft as foreign and mounts an immunological attack on the graft tissues. Most acute rejections occur in the first year.

Allocation The process of determining how organs are distributed. Allocation includes the system of policies and guidelines, which ensure that organs are distributed in an equitable, ethical and medically sound manner.

Allocation analysis Review of the allocation of an organ to determine whether the allocation policies were followed. The analysis is performed by the OPTN contractor through the peer review process of the OPTN Membership and Professional Standards Committee.

Allograft An organ or tissue that is transplanted from one person to another of the same species: i.e. human-to-human. Example: a transplanted kidney.

Anti-rejection drugs (immunosuppressive drugs) Drugs that are used to prevent and/or treat rejection of a transplanted organ.

Antibody A protein molecule produced by the immune system in response to a foreign body, such as virus or a transplanted organ. Since antibodies fight the transplanted organ and try to reject it, recipients are required to take anti-rejection (immunosuppressive) drugs.

Antigen An antigen is any substance that causes your immune system to produce antibodies against it. An antigen may be a foreign substance from the environment such as chemicals, bacteria, viruses, pollen, or foreign tissues. An antigen may also be formed within the body, as with bacterial toxins.

Biopsy A tissue sample from the body, removed and examined under a microscope to diagnose for disease, determine organ rejection, or assess donated organs or tissues.

Blood vessels The veins, arteries and capillaries through which blood flows in the body. Certain blood vessels can be donated and transplanted.

Brain death Irreversible cessation of cerebral and brain stem function; characterized by absence of electrical activity in the brain, blood flow to the brain, and brain function as determined by clinical assessment of responses. A brain dead person is dead, although his or her cardiopulmonary functioning may be artificially maintained for some time.

Candidate A person registered on the organ transplant waiting list. When an organ is offered on behalf of the candidate, he or she is then referred to as a Potential Transplant Recipient (PTR).

Cardiac Having to do with, or referring to, the heart.

Cardiac death Death defined as the irreversible cessation of circulatory and respiratory functions. Death is declared in accordance with hospital policy and applicable state and local statutes or regulation.

Chronic Developing slowly and lasting for a long time, possibly the rest of a person's life. For example: chronic kidney failure.

Chronic Disease Research Group (CDRG) A division of Minnesota Medical Research Foundation (MMRF). MMRF is the non-profit research subsidiary of Hennepin Faculty Associates, the academic medical group that staffs Hennepin County Medical Center, a teaching hospital in Minneapolis, Minnesota. The CDRG conducts research primarily focused in the areas of chronic kidney disease and organ transplantation. The MMRF-CDRG is responsible for the administration of the Scientific Registry of Transplant Recipients (SRTR).

Chronic rejection Slow, continuous immunological attack of the host immune system on the transplanted organ usually resulting in progressive loss of organ function.

Cirrhosis A disease of the liver in which normal, healthy tissue is replaced with nonfunctioning fibrous scar tissue and healthy, functioning liver cells are lost; usually occurs when there is a lack of adequate nutrition, an infection or damage caused by alcohol abuse.

Committees The OPTN currently maintains approximately 20 standing committees, a fluctuating number of ad hoc committees (established by the President to address a specific issue as it arises), subcommittees and joint subcommittees (created and maintained by standing committees). Committees are comprised of professionals, at least one Patient/Public representative, Minority Affairs Committee Representative, Pediatric Committee Representative, and one or more SRTR representatives. Permanent Standing Committees also include representatives from each of the 11 Regions. HRSA's OPTN Project Officer and Director of DoT, or their designees, serve as ex-officio non-voting members of all committees. Each committee is provided administrative, policy, analytic, clinical and technical support by one or more committee liaisons from the UNOS staff.

Corticosteroid A synthetic hormone used to reduce the body's normal immune reaction to infection and foreign tissue, such as a transplanted organ. Prednisone is a corticosteroid.

Criteria (medical criteria) A set of clinical or biologic standards or conditions that must be met.

Cyclosporine A drug used to prevent rejection of the transplanted organ by suppressing the body's defense system. Considered an immunosuppressant.

Deceased donor An individual from whom at least one solid organ is recovered or the purpose of transplantation after suffering brain death or cardiac death.

Deceased donor transplant The transplant of an organ from a deceased donor.

Department of Health and Human Services (DHHS or HHS) The department of the federal government responsible for health-related programs and issues.

Dialysis A mechanical process designed to partially perform kidney functions, including correcting the balance of fluids and chemicals in the body and removing wastes. See Hemodialysis and Peritoneal Dialysis.

Diastolic blood pressure The bottom number in the blood pressure measurement (80 in a blood pressure of 120/80), indicating the pressure in the arteries when the heart is at rest.

Division of Transplantation (DoT) DoT is the office within HHS/HRSA whose principal responsibilities include the oversight of management of the Organ Procurement and Transplantation Network (OPTN), the Scientific Registry of Transplant Recipients (SRTR) and the National Marrow Donor Program (NMDP) contracts; public education to increase organ and tissue donation; and technical assistance to organ procurement organizations (OPOs).

Domino transplant A procedure in which an organ is removed from one transplant candidate and immediately transplanted into a second patient, with the first patient receiving a new organ from a deceased donor.

Donate Life America Formerly the Coalition on Donation, Donate Life America is a national not-for-profit alliance of local affiliates and corporate partners that have joined forces to inspire all people to Donate Life through organ, eye and tissue donation. At the core of the organization's education efforts are the ongoing qualitative and quantitative research of public attitudes about organ and tissue donation and the development and dissemination of effective, motivating public service campaigns. Distributed at the national and community level, these multimedia campaigns effectively communicate two core messages: Transplants give people their life back, and here is how you can help. Founded by the transplant community in 1992, the Coalition publishes brochures, program kits and other materials; provides technical assistance, training, information and referral services; and coordinates the National Campaign for Organ and Tissue Donation. It is comprised of national organizational members and local coalitions across the U.S. that coordinate donation related activities at the local level. Volunteer advertising agencies work with the Coalition and its committees to develop targeted mass media campaigns.

Donation Service Area (DSA) The geographic area designated by CMS that is served by one organ procurement organization (OPO), one or more transplant centers, and one or more donor hospitals. Formerly referred to as Local Service Area or OPO Service Area.

Donor Someone from whom at least one organ or tissue is recovered for the purpose of transplantation. A deceased donor is a patient who has been declared dead using either brain death or cardiac death criteria, from whom at least one vascularized solid organ is recovered for the purpose of organ transplantation. A living donor is one who donates an organ or segment of an organ for the intent of transplantation.

Donor registries Available 24 hours a day, seven days a week, online registries provide authorized professionals access to a confidential database of registered organ donors, allowing easy and quick confirmation of an individual's consent to organ donation. All registries are voluntary and some are affiliated with the local motor vehicle bureau, while others are independently operated or OPO-based.

End-stage organ disease A disease that leads to the permanent failure of an organ.

Ethnicity For OPTN data purposes, the use of categories such as white, black or African-American, Hispanic, Asian, American Indian/Alaskan Native, Pacific Islander, multiracial.

Expanded criteria donor (ECD) kidney A kidney donated for transplantation from any brain dead donor over the age of 60 years; or from a donor over the age of 50 years with two of the following: a history of hypertension, the most recent serum creatinine greater than or equal to 1.5 mg/dl, or death resulting from a cerebral vascular accident (stroke). This definition applies to the allocation of deceased donor kidneys.

Functional status A way to measure the effects that lung disease may have on a person's ability to perform routine daily tasks. Functional status is used in the Lung Allocation Score.

Glomerular filtration rate (GFR) A measure used to determine kidney function, the GFR indicates the kidney's ability to filter and remove waste products.

Graft A transplanted organ or tissue.

Graft survival The length of time an organ functions successfully after being transplanted.

Hemodialysis A treatment for kidney failure where the patient's blood is passed through a filtering membrane to remove excess fluid and wastes.

Hepatic Having to do with, or referring to, the liver.

Hepatitis A viral infection or non-specific inflammation of the liver that can lead to liver failure. Hepatitis C is the leading cause of liver failure that leads to transplantation.

High blood pressure See hypertension.

Histocompatibility The examination of human leukocyte antigens (HLA) in a patient, often referred to as "tissue typing" or "genetic matching." Tissue typing is routinely performed for all donors and recipients in kidney and pancreas transplantation to help match the donor with the most suitable recipients to help decrease the likelihood of rejecting the transplanted organ. See Human Leukocyte Antigen System (HLA System).

Human immunodeficiency virus (HIV) A virus which destroys cells in the immune system, which makes it difficult for the body to fight off infections; toxins, or poisons; and diseases. HIV causes AIDS, a late stage of the virus characterized by serious infections, malignancies, and neurologic dysfunctions.

Hypertension High blood pressure. Occurs when the force of the blood pushing against the walls of the blood vessels is higher than normal because the blood vessels have either become less elastic or have gotten smaller. Hypertension causes the heart to pump harder to move blood through the body. It can cause kidney failure and heart disease if not treated.

Immune response The body's natural defense against foreign objects or organisms, such as bacteria, viruses or transplanted organs or tissue.

Immune system The organs, tissues, cells and cell products in your body that work to find and neutralize foreign substances including bacteria, viruses and transplanted organs.

Immunosuppression Prevention or inhibition of the immune system to respond to foreign substances in the body. Medications often used to prevent a recipient's immune system from rejecting a transplanted organ or tissue include prednisone, methylprednisolone, azathioprine, mycophenolate mofetil, cyclosporine, tacrolimus, and sirolimus, among others.

Immunosuppressive Relating to the weakening or reducing of your immune system's responses to foreign material; immunosuppressive drugs reduce your immune system's ability to reject a transplanted organ.

Induction therapy Medications given for a short finite period in the perioperative period for the purpose of preventing acute rejection. Though the drugs may be continued after discharge for the first 30 days after transplant, it will not be used long-term for immunosuppressive maintenance.

Infection A condition that occurs when a foreign substance, such as bacteria, enters your body, causing your immune system to fight the intruder. All transplant recipients can get infections more easily because their immune systems are suppressed. It is more difficult for them to recover from infection (such as urinary tract infections, colds and the flu).

Inflammation The swelling, heat and redness produced when the body is injured or infected.

International normalized ratio (INR) A measure of a patient's coagulation (clotting) system. INR is used in the MELD and PELD calculations.

Kidneys A pair of organs that remove wastes from the body through the production of urine. All of the blood in the body passes through the kidneys about 20 times every hour. Kidneys can be donated from living and deceased donors and transplanted into patients with kidney failure.

Leukocyte A white blood cell.

Liver The largest organ in the body, made up of a spongy mass of wedge-shaped lobes. The liver secretes bile, which aids in digestion, helps process proteins, carbohydrates, and fats, and stores substances like vitamins. It also removes wastes from the blood. A living donor can give part of their liver, after which the liver will regenerate itself in both the donor and recipient.

Match The compatibility between the donor and the recipient. The more appropriate the match, the greater the chance of a successful transplant.

Medicaid A partnership between the Federal government and the individual states to share the cost of providing medical coverage for recipients of welfare programs and allowing states to provide the same coverage to low-income workers not eligible for welfare. Programs vary greatly from state to state.

Medicare The program of the Federal government that provides hospital and medical insurance, through social security taxes, to people age 65 and over, those who have permanent kidney failure and certain people with disabilities.

Multiple listing Being on the waiting list for the same organ at more than one transplant center.

National Organ Transplant Act (NOTA) The National Organ Transplant Act (1984 Public Law 98-507), approved October 19, 1984 and amended in 1988 and 1990, outlawed the sale of human organs and provided for the establishment of the Task Force on Organ Transplantation; authorized the Secretary of HHS to make grants for the planning, establishment, and initial operation of qualified OPOs; and established the formation of the Organ Procurement and Transplantation Network (OPTN) and Scientific Registry of Transplant Recipients (SRTR).

New York Heart Association Functional Classification (NYHA) An assessment of a patient's heart failure based on the severity of symptoms. Range is Class I-IV.

Noncompliance 1) Failure of patients to follow the instructions of the medical team, 2) Failure of OPTN members to adhere to the policies and bylaws of the OPTN.

Organ A part of the body made up of tissues and cells that enable it to perform a particular function. Transplantable organs are the heart, liver, lungs, kidneys, pancreas and intestines.

Organ donation To give an organ or a part of an organ to be transplanted into another person. Organ donation can occur with a deceased donor, who can give kidneys, pancreas, liver, lungs, heart, intestinal organs, and with a live donor, who can give a kidney, or a portion of the liver, lung, or intestine.

Organ preservation Methods used to preserve organs while they are out of the body, between procurement from a donor and transplantation into a recipient.

Organ procurement The removal or retrieval of organs from a donor for transplantation.

Organ Procurement and Transplantation Network (OPTN) In 1987, Congress passed the National Organ Transplant Act that mandated the establishment of the OPTN and Scientific Registry of Transplant Recipients. The purpose of the OPTN is to improve the effectiveness of the nation's organ procurement, donation and transplantation system by increasing the availability of and access to donor organs for patients with end-stage organ failure. The Act stipulated that the Network be a non-profit, private sector entity comprised of all U.S. transplant centers, organ procurement organizations and histocompatibility laboratories. These members along with professional and voluntary healthcare organizations and the representatives of the general public are governed by a Board of Directors which reports to the Division of Transplantation, HHS and ultimately HHS. UNOS holds the OPTN contract.

Organ Procurement Organization (OPO) An organization designated by the Centers for Medicare and Medicaid Services (CMS) and responsible for the procurement of organs for transplantation and the promotion of organ donation. OPOs serve as the vital link between the donor and recipient and are responsible for the identification of donors, and the retrieval, preservation and transportation of organs for transplantation. They are also involved in data follow-up regarding deceased organ donors. As a resource to the community OPOs engage in public education on the critical need for organ donation. See also Donation Service Area (DSA).

Pancreas Irregularly shaped gland that lies behind the stomach and secretes pancreatic enzymes into the small intestines to aid in

the digestion of proteins, carbohydrates and fats. Islet cells within the pancreas secrete glucagon, which regulates blood sugar levels and insulin, which lowers blood sugar levels. If the pancreas fails, the individual becomes diabetic, and may need to take insulin. The pancreas can be donated and transplanted.

Panel reactive antibody (PRA) The percent PRA value is a measure of a patient's level of sensitization to HLA antigens. It is the percentage of cells from a panel of blood donors against which a potential recipient's serum reacts. The PRA reflects the percentage of the general population that a potential recipient makes antibodies (is sensitized) against. For example, a patient with a PRA of 80 percent will be incompatible with 80 percent of potential donors. Kidney patients with a high PRA are given priority on the waiting list. The higher the PRA, the more sensitized a patient is to the general donor pool, and thus the more difficult it is to find a suitable donor. A patient may become sensitized as a result of pregnancy, a blood transfusion, or a previous transplant.

PCO₂ A blood gas test is performed to measure the amount of CO₂ in the blood. When the lung's ability to exchange oxygen and CO₂ becomes impaired, the PCO₂ level may become increased. The candidate's current PCO₂ and change in PCO₂ are both considered in the lung allocation score calculation to reflect worsening PCO₂ values. PCO₂ is used in the Lung Allocation Score.

Peritoneal dialysis A treatment technique for kidney failure that uses the patient's own body tissues inside of the (abdominal cavity) to act as a filter. The intestines lie in the abdominal cavity, the space between the abdominal wall and the spine. A plastic tube called a "dialysis catheter" is placed through the abdominal wall into the abdominal cavity. A special fluid is then flushed into the abdominal cavity and washes around the intestines. The lining (peritoneum) of the abdominal cavity and of intra-abdominal organs act as a filter between this fluid and the blood stream. By using different types of solutions, waste products and excess water can be removed from the body through this process.

Plasmapheresis A process in which plasma is removed from blood and the remaining components, mostly red blood cells, are returned to the donor. The process may be used in transplantation to remove pre-formed antibodies.

Procurement The surgical procedure of removing an organ from a donor. Also referred to as recovery.

Pulmonary Having to do with, or referring to, the lungs.

Race See ethnicity.

Recipient A person who receives a transplant.

Recovery (organ) The surgical procedure of removing an organ from a donor.

Rejection A phenomenon that occurs when a recipient's immune system attacks a transplanted organ, tissue, or cell. Immunosuppressive drugs help prevent or treat rejection.

Renal Having to do with, or referring to, the kidneys.

Required request Hospitals must tell the families of suitable donors that their loved one's organs and tissues can be used for transplant. This law is expected to increase the number of donated organs and tissues for transplantation by giving more people the opportunity to donate.

Retransplantation Due to rejection or failure of a transplanted organ, some patients receive another transplant.

Retrieval The surgical procedure of organ recovery. Also referred to as procurement.

Risk pools State-created, nonprofit associations that do not require tax dollars for operational purposes. The risk pools are a temporary stopping place for individuals who are denied health insurance for medical reasons. Risk pools often help individuals who, because of their physical condition, are unable to purchase health insurance at any price.

Scientific Registry of Transplant Recipients (SRTR) As called for by the National Organ Transplant Act (NOTA), the purpose of the SRTR is to provide ongoing evaluation of clinical data about donors, transplant candidates, and recipients, as well as patient and graft survival rates. With oversight and funding from the DoT, the SRTR is currently administered by the Chronic Disease Research Group (CDRG) of the Minneapolis Medical Research Foundation (MMRF).

Sensitization Transplant candidates are "sensitized" if their immune system makes antibodies against a general donor pool. Sensitization usually occurs as a consequence of pregnancy, blood transfusions, or previous transplantation. The degree of sensitization is measured by panel reactive antibody (PRA). Highly sensitized patients are less likely to match with available donors and more likely to reject an organ than unsensitized patients.

Status An indication of the degree of medical urgency for patients awaiting heart or liver transplants. Examples: status 1A, status 1B, or status 2.

Steroids Naturally occurring hormones in the body that help control important body functions. Synthetic or man-made steroids can be used to suppress the immune system.

Survival rates Survival rates indicate the percentage of patients that are alive and the grafts (organs) that are still functioning after a certain amount of time. Survival rates are used in developing OPTN policy.

Systolic blood pressure The top number in the blood pressure (the 120 in a blood pressure of 120/80) measures the maximum pressure exerted on the vessel wall when the heart contracts.

Tissue An organization of a great many similar cells that perform a special function. Examples of tissues that can be transplanted are blood, bones, bone marrow, corneas, heart valves, ligaments, saphenous veins, and tendons.

Tissue typing A blood test that helps evaluate how closely the tissues of the donor match those of the recipient.

Uniform Determination of Death Act (UDDA) The 1981 Uniform Determination of Death Act is a model statute defining "brain death." Versions of this Act have been adopted in 39 states and the District of Columbia. The act states that an individual who has sustained either (a) irreversible cessation of circulatory or respiratory functions or (b) irreversible cessation of all functions of the entire brain, including the brain stem, is dead. A determination of death must be made in accordance with accepted medical standards.

United Network for Organ Sharing (UNOS) The private, nonprofit membership organization that coordinates the nation's transplant system through HRSA's OPTN contract. As OPTN contractor, UNOS is responsible for meeting all contract requirements. As contractor since the first OPTN contract award in 1986, UNOS has established and continually strives to improve tools, systems and quality processes that support OPTN contract objectives and requirements. These include:

- Managing the national organ transplant waiting list
- Collecting, managing and reporting of sensitive clinical data in a secure, fail-safe environment
- Facilitating an open, inclusive forum for development and continuous refinement of evidence-based policies and standards
- Member and policy performance assessment to ensure equitable, safe treatment of candidates and recipients
- Increasing donation and making the most of every organ that is donated through professional education, outcomes research, patient services and resources and public and professional education
- Continuously improving the care, quality of life and outcomes of organ transplant candidates and recipients

Varices (esophageal) Enlarged and swollen veins at the bottom of the esophagus, near the stomach. A common condition caused by increased venous pressure in the liver. These veins can ulcerate and bleed.

Vascular Referring to blood vessels and circulation.

Ventilator A machine that “breathes” for a patient when the patient is not able to breathe properly.

Virus A group of tiny organisms capable of growing and copying themselves while living within cells of the body.

Warm ischemic time (WIT) If the donor is a DCD donor, the warm ischemic time is the time from:

1. the time of Agonal Phase onset (from the time of cardiac arrest when the systolic pressure meets the following conditions for greater than five (5) minutes) to the time when core cooling is initiated. Agonal Phase onset:
 - a. Newborn up to 28 days, with a systolic blood pressure less than 60 mmHg, OR
 - b. 29 days up to 12 months, with a systolic blood pressure less than 70 mmHg, OR
 - c. 1 year up to 10 years, with a systolic blood pressure less than 70 mmHg, plus 2 times the age of the patient in years, not to exceed 79 mmHg, OR
 - d. 11 years or older, with a systolic blood pressure less than 80 mmHg, OR when the oxygen saturation is less than 80% at any age,
- The calculated time using the serial data to be collected beginning with the agonal phase and ending with the initiation of core cooling.

Xenograft An organ or tissue procured from a different species for transplantation into a human.

Glossary adapted from transplantliving.org, a UNOS website.

abbreviations

BMI	body mass index	LAS	lung allocation score
BRFSS	Behavioral Risk Factor Surveillance System	LD	living donor
CDC	Centers for Disease Control and Prevention	LVAD	left ventricular assist device
CDRG	Chronic Disease Research Group	MTOR	mammalian target of rapamycin
CMV	cytomegalovirus	NOTA	National Organ Transplant Act
COPD	chronic obstructive pulmonary disease	NYHA	New York Heart Association Functional Classification
CPRA	calculated panel reactive antibody	OPO	Organ Procurement Organization
CSA	cyclosporine A	OPTN	Organ Procurement and Transplantation Network
CSM	cyclosporine microemulsion	PAK	pancreas after kidney transplant
DCD	donation after cardiac death/donation after circulatory death	PPO	preferred provider organization
DD	deceased donor	PRA	panel reactive antibody
DHHS	Department of Health and Human Services	PTA	pancreas transplant alone
DM	diabetes	PTLD	post-transplant lymphoproliferative disorder
DOT	Division of Transplantation	RRT	renal replacement therapy
DSA	Donation Service Area	RVAD	right ventricular assist device
EBV	Epstein-Barr virus	SCD	standard criteria donor
ECD	expanded criteria donor kidney	SPK	simultaneous pancreas-kidney transplant
ESRD	end-stage renal disease	SRTR	Scientific Registry of Transplant Recipients
eGFR	estimated glomerular filtration rate	STAC	SRTR Scientific and Technical Advisory Committee
GN	glomerulonephritis	TAH	total artificial heart
HIV	human immunodeficiency virus	TCR	transplant candidate registration
HLA	human leukocyte antigen	TRR	transplant recipient registration
HMO	health maintenance organization	UDDA	Uniform Determination of Death Act
HTN	hypertension	UNOS	United Network for Organ Sharing
INR	international normalized ratio	USRDS	United States Renal Data System
KDRI	kidney donor risk index	VAD	ventricular assist device
		WIT	warm ischemia time